

Women's Chronic Pelvic Pain and Agenda Setting  
in the New Zealand Health System

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## CHAPTER ONE

### AGENDA SETTING AND THE POLICY PROCESS

#### Introduction

This chapter explains the rationale for this project and the central agenda-setting perspective adopted to investigate women's chronic pelvic pain (WCPP) in the New Zealand health system under the Labour government 1999-2008. This involves a brief examination of public policy, an outline of the place of agenda setting in the policy process and agenda-setting literature, and a sketch of interest group theory and social movement theory.

Recognition of the prevalence and impact of chronic conditions is increasing, both within New Zealand and internationally. This has occurred as improved medical interventions, and access to these, have seen chronic conditions replace communicable diseases as the leading cause of mortality (WHO, 2005b). Longer life expectancy, with an ageing population, also contributes to a situation where more people are in poor health (Kane, 1991).

The WHO has identified chronic conditions as one of the major health issues of the twenty first century in their global report document *Preventing Chronic Diseases: A Vital Investment* (2005), indicating that chronic diseases are now the leading cause of mortality worldwide, being responsible for at least 60% of all deaths, and predicting that 388,000,000 people would die of chronic diseases in the next ten years. It has also been identified elsewhere that chronic diseases are now the leading reason for seeking healthcare in the developed world (Dowrick et al., 2005).

This global situation can be seen in microcosm in New Zealand. The Ministry of Health (MOH) has identified chronic illnesses as the leading cause of preventable morbidity, mortality and unequal health outcomes in *Our Health Our Future* (1999), and states that chronic conditions account for more than 80% of deaths in this country (MOH, 1999). This concern is reiterated by the National Health Committee (NHC) in their report *Meeting the Needs of People with*



*Chronic Conditions* (2007), which addresses policy direction and service provision for those people with chronic conditions in New Zealand.

There is also growing awareness of the economic burden of chronic disease. In the United States, chronic conditions are thought to account for up to 75% of the country's health care costs (NHC, 2007); in New Zealand, the figure is comparable, with chronic conditions estimated to account for up to 70% of health spending (as cited in Gibbs & Taylor, 2008). The economic burden of chronic conditions consists of costs to the state, which are both direct (e.g. – medical care, pharmaceuticals) and indirect (e.g. – lost productivity, reduced employment), and to individuals, which are also both direct (e.g. – visits to health practitioners, medications) and indirect (e.g. – loss of income, economic toll). The 2007 NHC report indicated that chronic pain is associated with use of health care five times higher than average, longer hospital stays, and increase in morbidity (largely through interaction with depression). This indicates that the burden of chronic disease must be understood not only as physical and economic, but also emotional, psychological and spiritual.

There is recognition that chronic health conditions disproportionately affect already disadvantaged groups within society, and thus both illustrate and perpetuate the problem of inequalities in health. In the New Zealand context, this means that “chronic conditions disproportionately affect Maori, people living on low incomes, and Pacific peoples...(due to) poor access to preventative measures, treatment for and management before chronic conditions relative to other populations” (NHC, 2007, p. 10).

### Women's Chronic Pelvic Pain

Women's chronic pelvic pain (WCPP) is one example of such a chronic condition. While men also suffer from chronic pelvic pain, the condition is much more common in women. A New Zealand population-based study in 2001 found that 25.4% of women experienced chronic pelvic pain (Grace & Zondervan, 2004). While WCPP is not directly associated with mortality, it may be indicative of some gynaecological cancers, and the experience of chronic pelvic

pain and its associated symptoms can be burdensome to the individual, their caregivers/support networks, and the health system. The economic burden may be substantial; Mathias et al. (1996) estimated that in the United States, the cost of physician visits was \$881.5m and out-of-pocket expenses \$1.9b, while the cost in terms of time lost from work was estimated at \$555.3m.

WCPP is rare among chronic conditions in that it disproportionately affects younger women (i.e. – prevalence decreases with age) (Le Resche, 2000). Underlying pathology may also contribute to infertility (up to 40% of women's fertility problems are believed to be due to endometriosis (Krotec & Perkins, 2007)), which further exacerbates the problem.

WCPP, then, is obviously an important health issue facing New Zealand women. It is also an important issue for policymakers. The issue involves a variety of different perspectives and realms of expertise, making it an interesting one for a study of agenda setting, a process inherently about the balancing of these competing viewpoints (Lewis & Considine, 1999).

### **Agenda Setting**

An understanding of agenda setting is central to this study. Agenda setting is “the process by which problems come to the attention of governments” (Howlett & Ramesh, 2003: p.13). Taking this approach to the issue of WCPP allows comparison with other health issues and a consideration of how WCPP can advance as a policy issue. Because agenda setting is recognised in the extensive policy literature as an early stage of the policymaking process, an understanding of this process is also beneficial.

### **The Policy Process**

Agenda setting takes place within the policy process. A number of authors have attempted to describe this process by outlining a series of *stages* through which policy progresses. These largely follow the same pattern, varying by degree of specificity and whether the process is seen to end with implementation or include

further stages, such as evaluation, maintenance, succession or termination. Table 1.1 demonstrates the similarities evident among recent authors Howlett and Ramesh (2003) and Palmer and Short (2003) and earlier theorists Brewer and deLeon (1983), Jenkins (1978), and Hogwood and Gunn (1984), who elaborate upon the decision-making stages. Such ‘staged’ approaches to the policy process have been criticised for being too regimented, and for failing to account for both the variations in the policymaking process in the real world, and feedback loops. It is obvious that “the dividing lines between the various activities are artificial and policymakers are unlikely to perform them consciously or in the implied ‘logical’ order” (Hogwood & Gunn, 2001: p. 4). Thus the ‘stages’ are likely to be more useful for policy analysts and researchers than policymakers.

Table 1.1 Policy models

Jenkins (1978)	Brewer and deLeon (1983)	Hogwood and Gunn (1984)	Palmer and Short (2003, following Anderson, 1984)	Howlett and Ramesh (2003)
initiation	initiation	issue search	agenda setting	agenda setting
information	estimation	issue filtration	policy formation	policy formulation
consideration	selection	issue definition	adoption	policy implementation
decision	implementation	forecasting	implementation	decision making
implementation	evaluation	setting objectives and priorities	evaluation	policy evaluation
evaluation	termination	options analysis		
termination		policy implementation, monitoring and control		
		evaluation and review		
		maintenance, succession or termination		

Such approaches also tend to follow a rationalist model of policymaking, which “treats policy-making as a problem-solving activity” (Tenbensen & Gauld, 2001: p. 25). Policymakers are assumed to make fully informed decisions from a clearly specified set of alternatives in order to achieve goals and objectives that have been determined in advance. This model is problematic, as it is heavily dependent on the role of experts (and the quality and extent of their knowledge), is time-consuming, and ultimately rests upon the values of those informing decision makers. As Sabatier (1999) notes, the policy process in fact involves a number of different elements, which not only interact with each other, but do so in *different ways over time*, including actors with different values, interests, perceptions and policy preferences; large time spans; different programs, involving multiple levels of government; debates and technical disputes; and, disputes involving values, money and authority.

Of course, the rationalist model is not the only one available to theorists and policymakers. Palmer and Short (2003) have described the two primary alternatives as incrementalism, which understands policymaking as a series of small adjustments to previous policies; and mixed scanning, which is essentially a compromise between the two, so that a rational approach is taken to setting out alternatives, and an incrementalist approach taken to choosing between them. Like the rationalist model, these are imperfect; incrementalism fails to comprehensively redress policy objectives and tends to lead to conservative policies, while mixed scanning, by its very nature, consists of faults from each model.

Despite these differences, there appears to be consensus about the *nature* of policymaking, universally understood as a *process*. This “connotes temporality, an unfolding of actions, events and decisions that may culminate in an authoritative decision” (Schlager, 1999: p. 233). Gerston (1997) describes this process as

“dynamic and ongoing...constantly subject to reevaluation, cessation, expedited, or even erratic movement...policy-making exists in an open environment with neither a beginning nor an end, and with virtually no boundaries” (p. 5).

It is worth noting too that policy may not always be linked to decision-making processes in the ways these authors have implied; policy may also be an outcome in itself. Hill (1997) has highlighted different foci in studying policy, including that of policy content, policy outputs, evaluation studies and policy advocacy. Furthermore, policymaking involves not only decisions and action, but also non-decisions, “the practice of limiting the scope of actual decision making to ‘safe’ issues by manipulating the dominant community values, myths, and political institutions and procedures” (Bachrach & Baratz, 1963: p. 632) and inaction (Hill, 1997).

Complicating this process of policymaking, however, are the different motivations that may drive it. Policymaking has been described as the balancing of competing goal orientations, such as individual freedom and choice; social or public good; scientific and technological progress; quality of life; human dignity; efficiency; social stability; and alternative concepts of justice (Blank, 1995). Similarly, varying human needs and values have to be balanced in policymaking, including: power (participation in decision making; enlightenment (insight, knowledge, information); wealth (income and property); well being (health, safety, comfort, and security); skill (proficiency in performing tasks); affection (love, friendship, loyalty, solidarity); respect (honour, status, reputation, non-discrimination; and rectitude (conforming with ethical or religious standards) (Brewer & de Leon, 1983).

While policymaking in health follows the same processes as public policy more general, other models of policymaking may seem more applicable to health policy, given the different values that may apply. Tenbensel and Gauld (2001), in their study of models and theories in New Zealand health policy, outline other models, including stakeholder models, which focus upon the interactions and power relationships between different policy actors with interests in a particular area; participatory models, which focus on the ‘democratic’ aspects of policymaking and emphasise the benefits of public consultation and deliberation; and, neoliberal models, which focus on market-oriented approaches and envisage a minimal role for the state.

These authors note that these models, too, are flawed. The stakeholder model may allow for a detailed analysis of policy development on a particular issue, but are less useful in accounting for broader trends. Participatory models tend to describe an ideal situation rather than a realistic one, and may also be impracticable. Neoliberal models may result in compartmentalisation and service provision failure (Tenbensen & Gauld, 2001).

These models allow an insight into the nature of policymaking, but they do not provide the whole picture. Policy analysts may take different approaches to get a 'better look', through the lenses of class analysis; actor-centred institutionalism, the analysis of appropriate institutional behaviour based on the nature of economic transactions; sociological individualism/welfare economics, which places responsibility for correcting 'market failure' on government; pluralism (a form of stakeholder model as described by Tenbensen and Gauld (2001)), which focuses on the role of interest groups in the political process; corporatism, which also focuses on groups, but envisages a greater role for the state and pays greater attention to the interactions between interest groups and government; and, statism, which emphasises organisational structures and political institutions (Howlett & Ramesh, 2003).

Policymaking in New Zealand is normally understood in a pluralist sense, and like other developed countries, it undergone a series of neoliberal reforms (Prince, 2006). Governments have also been constrained by a strong belief that the public should have an active participatory role, even though this ability is increasingly illusory (Blank, 2001). The New Zealand health system and the privileged status of health in society will be discussed further in Chapter 2.

### Agenda setting literature

The term 'agenda' can be used to indicate different things. At its most simple, it refers to "the things people talk about" (Riker, 1993: p. 2). A common distinction is between 'formal' and 'public' agendas, where public agenda refers to those issues that have attracted a high level of public attention and interest, and the formal agenda those

issues that have been accepted and officially identified by government as requiring consideration (Cobb, Ross & Ross, 1976). A similar distinction is that between the substantive and symbolic agenda; those issues on a substantive agenda involve the allocation of a significant amount of public resources, generate large amounts of interest and contain the potential for change, whereas items on the symbolic agenda will focus more on values than resources (Gerston, 1997). Kingdon acknowledges that within the formal agenda, which he describes as the governmental agenda, there are also specialised agendas (e.g. – in health care, education, transportation) and decision agendas (i.e. – those issues actively being decided upon) (Kingdon, 1995 [1984]). Kingdon thus defines a policy agenda broadly as “the list of subjects or problems to which governmental officials, and people outside of government closely associated with those officials, are paying some serious attention at any given time” (p. 3). He also highlights the difference between an agenda and the specification of alternatives, which are those measures that might be used to address an agenda item, a distinction often blurred elsewhere.

For the purposes of examining the issue of WCPP, a ‘policy’ and ‘public’ agenda, will be examined, following Kingdon’s definition of a policy agenda, and treating the public agenda in the common sense of those issues attracting public interest and attention.

As can be seen from the overview of the policy process, agenda setting is often considered to also incorporate problem identification, filtration and definition. While some authors prefer to separate the two processes (Kingdon, 1995 [1984]), this last stage often also incorporates the outlining of policy alternatives. Dery (1984) explains that issue identification occurs when it becomes apparent that there is a discrepancy between what *is* and what *ought to be*. This process may function as “a learning medium for what we may realistically aspire to achieve” (p. 9), and thus the definition process is effectively one of “stage setting, which creates or defines certain activities as solutions” (p. 6). This may all depend on the *type* of issue at hand.

Cobb and Elder’s agenda-building framework (1971) has attempted to highlight the commonly neglected agenda-setting stage of the policy process, emphasising the role of pressure groups and the public in contributing to the policy process

through their part in forming the agenda and reconfigure contemporary notions of democratic participation. They emphasise barriers faced by these pressure groups and the wider public clear, namely, the prevailing biases and inertia of the political system and the lag experienced between issues being advanced from outside government and taken up onto formal policy agendas (which Cobb and Elder term the 'institutional' agenda). This explanation of the predilection towards older issues remains one of the greatest contributions made by their work.

It is clear that the agenda-building framework outlined here has been modelled on the American experience and is only fully applicable to pluralist societies. Within these confines, however, Cobb and Elder (1971) have also provided a useful account for the differential responsiveness of decision makers to issues, suggesting that decision makers may be identify as a member of a group, or somehow feel indebted to the group, or that the group itself may have more resources, a greater ability to mobilise these resources, greater public esteem or strategic location. These factors are certainly worth considering in a New Zealand context, and go some way to explaining the place of WCPP on the policy agenda in New Zealand.

Cobb, Ross and Ross (1976) have also presented three conceptual models of agenda setting: outside initiative, in which issues arise in non-governmental groups and are then expanded; mobilisation, in which issues arise within government, thus having a virtually automatic place on the agenda, but require expansion to the public agenda also; and, inside initiative, in which issues arise within government, and attempts are made to restrict them to this sphere. In each of these models, there occur four stages: initiation, specification, expansion and entrance. The authors state that within the outside initiative and mobilisation models, groups have certain strategies available to them (in the inside initiative model, these same strategies are not needed), such as violence, institutional sanctions, working through brokers (e.g. – political parties and interest groups) and direct access. The strategy chosen will depend on the position of the group in society; the importance of the issue to the group; the length of time the issue has remained on the public agenda without moving to the formal agenda and the group's



estimate of probability of moving to formal agenda from use of each strategy (Cobb, Ross & Ross, 1976). These models are again heavily influenced by the American experience and apply only to pluralist states.

An alternative formulation has been offered by Sabatier and Jenkins-Smith's Advocacy Coalition Framework (ACF) (1993), which focuses on the interaction of 'advocacy coalitions': collections of actors, from a variety of institutions, who share a set of policy beliefs (Sabatier, 1999, 1998). The ACF diverges from those preceding it in emphasising the importance of time; policy change in this model can only be understood in the context of at least a decade. Policy change is understood to be the outcome of interaction of competing advocacy coalitions within a policy subsystem, events external to the policy subsystem and the effects of stable parameters on the constraints and resources of actors in the subsystem (Jennings, 2004).

Kingdon (1995 [1984]) has also provided a novel way of approaching policy agendas, seeing them as being comprised of three 'streams': problems, policies and politics. He suggests that items reach the agenda when these three streams converge: "(a) problem is recognised (problem stream), a solution is available (policy stream), the political climate makes the time right for change and the constraints do not prohibit action (political stream)" (p. 88). Kingdon notes that problems are often recognised due to 'focussing events' or crises, although these generally need to be accompanied by a pre-existing awareness of the problem, early warning, or in conjunction with other events that highlight the problem. A systemic agenda item may be advanced by attaching itself to a focussing event in order to reach the formal agenda.

The policy stream is seen as made up of policy communities, comprised of policy actors and entrepreneurs. Kingdon suggests that these policy actors may participate in this stream for the promotion of their personal interests or values, to affect public policy, or simply to be involved in 'the game'. He notes that "policy making is often a process of creating intellectual puzzles, getting into intellectual binds, and then extracting people from these dilemmas" (p. 126). These processes of argumentation and deliberation, while important, may

significantly slow the policy process, or even prevent an item from reaching the agenda if it is seen as intellectually dissatisfying or unworthy.

The political stream is comprised of things that might be considered 'political' in quite a narrow sense: pressure group campaigns, election results, changes of administration, public mood, etc. The political stream is important because it is in this stream that assessment of support for an agenda item occurs. Furthermore, if there is no individual or agency within the political stream who can be held responsible for the agenda item (i.e. – someone whose jurisdiction it would fall under), then the issue may fail to reach the agenda).

Points of convergence occur in 'policy windows', Kingdon's term for times when there is possibility for change. These windows open in the political stream, may be unpredictable, and are infrequent and brief; indeed, it may not even be clear that a policy window has opened. This important contribution to this area of inquiry can seem discouraging in the sense that it seems to leave a great deal simply to chance, in the coincidence of convergence. In this formulation, the actor's role is thus to work for the convergence of the three streams, 'soften up' policymakers on the issue, wait for and successfully identify policy windows. Kingdon characterises the agenda-setting process as competitive but acknowledges that the opening of a policy window in one issue increases the chances of one opening for a similar project. He suggests that new principles may be formed, and "part of the importance of establishing a new principle lies in its logic: A precedent is set, so future arguments surrounding the policy are couched in different terms. But part of it is political: An old coalition that was blocking change is defeated, and life is never quite the same" (p. 191).

Baumgartner and Jones' 'punctuated equilibrium' theory seeks to account for rapid policy change, as well as incremental change, which is more commonly emphasised in policy and agenda-setting models, as evidenced from those discussed thus far. Punctuated equilibrium theory describes a policy process conceived of as characterised by long periods of stasis, 'punctuated' by periods of crisis (True, Jones & Baumgartner, 1999). Legro (2000) has attempted to account for the same kind of rapid change by identifying processes of collapse

(when actors reach an agreement that the status quo is inadequate), followed by consolidation (when there is social coordination on a replacement set of ideas).

Baumgartner and Jones' theory emphasises the issue definition and agenda-setting stages of the policy process, and suggests that interaction between policy venues and image account for these times of rapid change. A policy venue is described as a political institution (the use of 'political' can here be understood in a broad sense). The 'image' of a policy refers to the beliefs and values expressed about a policy, and can be understood from the terms it is discussed and whether it is projected in a positive or negative way (Baumgartner & Jones, 1991). These authors attempt to shift the focus of agenda-setting studies to these sorts of issues, identifying the common assumption that issues reach the agenda through a process of issue expansion (i.e. – interested actors mobilise others to promote the issue), but suggest that the role of policy venue should be considered more carefully here. They describe a process of 'venue shopping' by actors, where venues are selected on the basis of their likelihood to yield results (Baumgartner & Jones, 1991). This work is useful to analysts and advocates alike, both of whom are able to better understand the complexity of the policymaking process through this model.

### Interest groups

Interest groups, also called pressure groups, political groups, lobby groups and voluntary associations, have been defined by Mulgan (2004 [1994]) as "an organised group representing to government the views of those who share a common interest" (p. 208). They may emerge in part because of the perception of politics as "remote, set apart, omnipresent as the ultimate threat or means of succour, yet not susceptible to effective influence through any act we as individuals can perform" (Edelman, 1985 [1964]: p. 6). Interest groups are an important part of political participation in any society and study of them instructive in attempts to understand the relationship between government and society (Wilson, 1990). Interest groups are normally linked to pluralist societies (Ham & Hill, 1984) and may have different relationships with government. Mulgan (2004 [1984]) has described these relationships as falling into the categories of open/*laissez-faire* pluralist, where the

political system is like an open economic market and private individuals organise themselves into (competing) interest groups in order to gain benefits from government; corporatist, where interest groups are formally incorporated into the system of government; and market liberalist, which rejects the pluralist view of politics and the legitimacy of interest groups, which are considered only self-interested and seeking privileges (Mulgan, 2004 [1994]). It is important to note also that it is not only the actual activities of interest groups, but their existence also, that creates pressure (Bentley, 1993).

The criticism offered by the market liberalist view is not uncommon. Interest groups are often seen as “inhibitors of democracy, ‘special pleaders’ using unseemly tactics to wrangle favours from legislators” (Baumgartner & Leech, 1998: pp. 84-85). Interest groups are feared to deadlock and fragment the political system, and they are sometimes thought to “represent narrow, selfish, and, for the most part, upper-class interests” (Walker, 1991: p. 21). It may be that interest groups tend to “favour long-standing interests which have had time to establish their organisations and political contacts...(and) sectional interests at the expense of the interests of consumers and the public at large” (Mulgan, 2004 [1994]: p. 230). In these ways, they may perpetuate inequalities: “the wealthy against the poor, the established against the up-and-coming, and sectional interests against the public interest” (Mulgan, 2004 [1994]: p. 230-231). Such criticisms are based on an understanding of interest groups as essentially rational, following their own self-interest, which, given the diversity of interest groups and of members within groups, is often far from the case (Olson, 1993). However, interest groups need not necessarily be understood in these terms; they may also work to increase the number of issues gaining attention (Walker, 1991) and help to ensure diversity and representation of opinion (Baumgartner & Leech, 1998). Cobb and Elder (1971) have even gone so far as to suggest that the perceived legitimacy of the group advancing an issue will be more important to its success than that of the issue itself.

Gais and Walker (1991) suggest that the activities of interest groups can be categorised as either ‘inside’, which are those designed to convince public officials to take a course of action, or ‘outside’, which are those intended to build support within the general public for a new set of values that may eventually be manifested in policy.

They state that the choice between these two activities is usually made earlier in a group's history and is unlikely to change, except in extreme circumstances. It will be made on the basis of which is thought to give the greatest chance of survival, the organisational resources of the group, the character of the group's membership and sources of financial support.

Similar characteristics are held to determine the power of interest groups (Signal, 1998). Interest groups are considered to have become more powerful in health issues, as they are now seen as legitimate stakeholders, "bringing to the policy process and important resource – experiential knowledge, expertise and networks..." (Allsop, Baggot & Jones, 2002: p. 62).

The majority of interest group activity in New Zealand occurs within Mulgan's *laissez-faire* model, although agricultural and indigenous interests could be seen as operating within something closer to the corporatist model (Mulgan, 2004 [1994]).

Social movements may also act as interest groups (Richardson, 1993) and they are an important part of both politics and health issues like WCPP. The term 'social movement' has been coined to highlight the shift in social movements resulting from a post-industrialist economy and concerns around issues such as the rights of minority groups. These new social movements act as both producers and consumers of knowledge:

"As producers of knowledge, social movements forge collective identities, give meaning to social problems, engage in the imaginative process of connecting issues, and translate social science into popular beliefs and moral obligations. As consumers of knowledge, they gather, select, and use scientific and technological information as a commodity in lobbying governments on specific policy issues and in persuading the public to understand issues in particular ways" (Phillips, 1994: p. 57).

The rise of these new social movements is theorised to result in a 'democratisation' of everyday life as they essential form a type of identity politics, where there is motivation to represent interests to the state, as well as form and participate in

organisations and events that form collective identity (Phillips, 1994). Those within these movements become lay experts (Dumit, 2005) and they may take the role of policy entrepreneur or activist.

## **Conclusion**

Understanding the policy process and agenda-setting approach is a necessary precursor to a consideration of WCPP in the New Zealand health system. Chapter 2 will discuss this health system in greater detail, focusing on the different explanatory frameworks in health and illness, and exploring the problem of medicalisation. Chapter 3 will investigate the place of WCPP on the policy and public agendas in New Zealand, and attempt to explain the reasons for this. A comparative analysis of endometriosis and breast cancer follows in Chapter 4. This chapter aims to illustrate the reasons for the prominence of breast cancer as an issue, and compare this success as an agenda item with that of endometriosis. The final chapter will draw together the arguments being made, and attempt to provide a path forward for WCPP, in terms of agenda setting.

## CHAPTER TWO

### HEALTH, ILLNESS AND MEDICALISATION

#### Introduction

This chapter outlines the key literature that surrounds women's chronic pelvic pain. This literature also frames the perspectives through which issues of health, illness and disease have been constructed and analysed. In New Zealand, this has been through three main explanatory frameworks: biomedicine, public health and environmental health. After a brief examination of the literature on health and illness, these frameworks, and their limitations are explored. The issue of medicalisation in each of these frameworks is then outlined, with particular attention to the medicalisation of women's bodies.

#### Health and illness

The term 'health' is frequently used in our society, and may denote many different things. Binary understandings of health (i.e. – health as *not* being ill) have been superseded by much more complex and diverse explanations. Illich (1976) has explored different meanings of the word 'health':

“an everyday word that is used to designate the intensity with which individuals *cope* with their internal states and their environmental conditions” (p. 14).

This understanding of health means that

“to be in good health means not only to be successful in coping with reality but also to *enjoy* the success; it means to be able to *feel alive* in pleasure and pain; it means to *cherish* but also to *risk survival*” (pp. 133-134).

However, the term may also refer to

“the range of autonomy within which a person exercises control over his own biological states and over the conditions of his immediate environment...health is identical with the degree of *lived freedom*” (p. 244)

as well as

“a *process of adaptation*...It designates the *ability to adapt* to changing environments, to growing up and to ageing, to healing when damaged, to suffering, and to the peaceful expectation of death. Health embraces the future as well, and therefore includes anguish and the inner *resources* to live with it” (p. 273)

or

“a *process* by which each person is *responsible*, but only in part responsible to others” (p.273, all italics added).

Lupton (2003) has identified yet another understanding of health as “a *goal*, to be achieved by intentional actions, involving restraint, perseverance and the commitment of time and energy” (p. 43), while others have seen health as a cultural construct (MacDonald & Park, 2005). The WHO has consistently presented health as “a *resource* for everyday life, not the objective of living” describing health as “a positive concept emphasising social and personal resources, as well as physical capabilities” (WHO, 1986). These sorts of sweeping definitions have been criticised as overly inclusive (Purdy, 2001), and there is certainly a danger that they become meaningless in their breadth.

The concept of illness has also drawn considerable attention, particularly from medical sociologists, and there is similar variance in how it is approached. Gerhardt (1989) has developed a framework of sociological approaches to illness, which traces the development of ideas about illness in this discipline. The structural functionalist model, as characterised by the work of Parsons (1975), understood illness as related to role struggles and medicine was seen as a microcosm of the structure of society. An anti-Parsonian trend in medical sociology followed, giving rise to the symbolic interactionist model, which emphasised the social, cultural and environmental aspects of health. While these both legitimate biomedicine, Gerhardt suggests these have been superseded by models more critical of biomedicine: the phenomenological, which understands illness as inter-subjective and emphasises the role of knowledge; and conflict-theory, which conceives of conflict as a basic part of life, and sees illness as both a failure of resources and ideological construct.



The literature on health, illness and disease distinguishes between acute and chronic illness, often describing another 'layer' to illness when it occurs over time (Bury, 1991). WCPP, as a chronic condition, is commonly understood within these (extended) parameters. Charmaz (1999) has suggested that chronic illness is:

“at once subjective and social; it...means much more than feeling physical distress, acknowledging symptoms, and needing care. It includes metaphor and meaning, moral judgments and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles...it challenges prior meanings, ways of living that have been taken for granted, and ways of knowing self” (Charmaz, 1999: p. 277).

The editorial of the first issue of the *Chronic Illness* journal outlined the problem clearly: “Chronic illnesses are prolonged, do not resolve spontaneously, and are rarely completely cured” (Dowrick et al., 2005: p. 1), and this certainly describes WCPP. Of course, the key distinguishing feature of chronic illness is that it is *ongoing*. This difference in experience between acute and chronic illness is therefore closely linked to the value we place on time, which is so fundamental to our perception of the world that we do not even generally have to think about it. Time functions as a unit of economic value, a resource, and something to be filled, and in these ways is “not a natural phenomenon, (but) rather it is a cultural attribute which is constructed and utilised socially” (Fox, 1999: p. 73). Chronic illness therefore takes on a particular cultural significance, and may inflict suffering of a different nature to acute illness also. This is further complicated by the fact that chronic illness is rarely a matter of the *same* experience over time; chronic illness often consists of periods of both remission and recurrence, whether over a matter of days, weeks, months or years. In cases such as WCPP then, women may feel “not only incapacitated but bereft of explanation” of these changes in their condition (Bendelow, 1995: p. 150).

Chronic illness is commonly understood to be a phenomenon of the twentieth century (Royer, 1998), and it is often held that there has been an increase in the prevalence of chronic disease, particularly in the second part of that century. However, Armstrong (2005) argues that this increase is largely socially constructed, suggesting that this apparent increase is at least partly a matter of increased recognition, and describing it as

a *social* phenomenon rather than an *epidemiological* one. This certainly seems a reasonable supposition in terms of WCPP, which we can reasonably assume has been ‘discovered’ as a condition, rather than having simply emerged from nowhere.

### **The New Zealand Health System**

The health system in New Zealand has undergone a number of changes in the past 150 years, driven in large part by ideological change at a societal level. Belgrave (2008) outlines these from the point of the 19<sup>th</sup> century, which was characterised by the economic philosophy of *laissez-faire* and the corresponding emphasis on individual and familial responsibility (and therefore a deliberate lack of state provision). He traces the beginning of the welfare state in New Zealand to the early 20<sup>th</sup> century, and fears of population decline and a weakening of the race. By World War Two, this had formed into a public health discourse about an ‘ideal’ society (still comprised of ‘ideal’ families). This underwent a major shift with the rise of neoliberalism in the 1980s, when belief in the market and the doctrine of individualism meant an emphasis on patients’ rights and consumer choice. Belgrave argues that neoliberal discourse on health has also tended to suggest that individuals are each subject to the same health risks, which has undermined political support for state intervention in health.

McKinlay and Marceau (2001) have explored the impact of such ideological changes on the medical profession in the United States, and the relationship of medical professionals to their patients. They suggest that the dominance of the medical profession throughout most of the twentieth century has changed in part because of factors also relevant in New Zealand, such as the changing nature of the state, the bureaucratisation of doctoring, the erosion of patient trust, and changes in both the cultural concept of the body and modern epidemiology (from cure to care).

After a series of health reforms, the New Zealand health system now consists of ministerial control, with the MOH functioning as the principal advisory body. 21 District Health Boards (DHBs) are responsible for the provision of services in their (geographic) districts, and Primary Health Organisations are the primary

means of primary care provision. There are also 12 Public Health Units around the country, providing regional services, primarily environmental and health promotion services, as well as a number of Crown entities, such as the Health Research Council, and advisory committees (MOH, 2009). Non-governmental organisations (NGOs) also have a crucial role to play, and there is now a Health and Disability NGO Working Group working with the MOH (Health and Disability NGO Working Group, 2008).

This system was devised by the Labour government, seeking to replace the commercially-oriented system of previous National governments with a more community-focused system (Ashton, 2005). Despite the benefits yielded from this, there are still concerns about the problems plaguing the health system: a so-called schism between managers, clinicians and public health advocates; the orientation of DHBs to hospitals and throughput figures; poor industrial relations; the undervaluing of general practitioners; reliance on overseas-trained doctors; student debt; and inequalities in health outcomes (Gorman & Kolbe, 2008).

The Labour government of 21st century has been described as employing 'third way' health policy, which attempts to balance and reconcile different approaches. Belgrave (2008) has stated that this has involved a move towards population-based health services and increased funding, but also bemoans the lack of success in addressing inequalities more broadly (especially given the economic growth generally enjoyed during their term).

Gostin (2004) has argued that health should be considered a public value because a "safe and healthy population builds strong roots for a country...a certain level of human functioning is a prerequisite for engaging in activities that are critical to the public welfare" (p. 10). In a general sense, governments have a number of powers available to them, many of which can be utilised to assure conditions for health, including the power to tax and spend, to alter the informational, built or social environment, direct regulation (of person, professions and businesses), indirect regulation (through torts) and deregulation (Gostin, 2004) as well as community, school and workplace interventions, screening, clinical prevention, disease

management, rehabilitation and palliative care (WHO, 2005b). In New Zealand, there is a strong tradition of state involvement in health, and there is a high level of both central (government) control of, and accountability for, the health system, with a unicameral legislature and high levels of party discipline (Fougere, 2001). The government is also the primary source of health funding, with figures remaining stable (around 77%) for the past fifteen years; in 2005/6, this amounted to \$12,014m (77.9%) (MOH, 2008). Health expenditure as a percentage of total government expenditure, however, has increased in the past decade, from 13.1% in 1996 to 18.6% in 2006 (WHO, 2009).

Nonetheless, health policy is a particularly difficult area for governments. The area is also plagued by the absence of statistical material, the lack of well developed theories and the vast number of external factors that lie beyond policymakers (Palmer & Short, 2003).

### The privileged status of health

Health policy is also a difficult area because questions of health and illness are always highly charged, as the notion of health occupies a special place in Western society. Opinion polls demonstrate that health is routinely a major election issue in New Zealand, and often the primary one (Fougere, 2001). Gostin (2004) has asserted that “health is foundationally important because of its intrinsic value and its singular contribution to human functioning...necessary for much of the joy, creativity, and productivity that a person derives from life” (p. 10). Blank (2001) in his study of health policy in New Zealand, has noted that “(o)f all areas of policy, health care is one of the most emotional and controversial...This should not be surprising given the high stakes involved in any government policy involving life, death, and huge amounts of resources, and the fact that all citizens risk being at the mercy of health care decisions” (p. 149).

The provision of health care is generally felt to be a different kind of service to others, and health is a politically loaded topic. It has been suggested that this is because of the wide-ranging effects of health status on a person's life (Blank & Hines, 2001). It is an issue concerned with elementary human need and suffering, is

highly complex, requires knowledge and expertise, meaning that there is an important role for the medical profession, and poor care may be disastrous (Palmer & Short, 2003; Friedson, 1989).

Within this health system, and society which so highly values health, there have been three main explanatory frameworks that have shaped understanding of health, illness and disease. These are now explored in turn.

### **The Biomedical Approach**

Biomedicine, also referred to as Western medicine, cosmopolitan medicine, clinical medicine, modern medicine, hospital medicine, and pathological medicine, is the dominant means by which we understand the body, health, illness and disease in Western culture. The term refers not only to a body of knowledge, but also of know-how, a professional group, and technologies (Pierret, 2003), and should be understood as both a technical language and a value system (Loustanaou & Sobo, 1997). The 'bio' in biomedicine points to the prominence of the natural sciences (e.g. biology and physiology) in medical practice.

The biomedical approach is characterised by its organisation around diseases (Moore et al., 1980), which are

“perceived as disruptors of the body’s normal functioning: as abnormal and pathological. (In biomedicine, we) ‘get it’, ‘catch it’, ‘get rid of it’, ‘shake it off’...The illness itself is seen as unproblematic...as discrete physical entities, no matter in which culture or individual they occur, or who has the power to diagnose them. Illnesses in this approach are pre-existing categories, discovered but not invented by human beings: they have a life independent of social structure and social organisation” (Karpf, 1988: p. 10).

This puts a great deal of power in the hands of those people with the expertise to interpret these categories, and again reinforces the role of technocratic expertise, as mentioned earlier. A hierarchy of disease may appear, at the bottom of which are those conditions with symptoms that cannot be adequately explained by current

biomedicine or its science, and thus do not fit the biomedical framework. The problem with this is that those suffering from conditions at the bottom of this hierarchy are not likely to get the attention they require (Nettleton et al., 2004; Aronowitz, 2001).

Biomedicine is inclined towards explaining illness and disease at ever more specific levels, from that of subjective experience, to organ systems, to cellular derangement (Aronowitz, 2001). According to Patel (2002), the use of biomedical technologies occurs so that parts of the body can be seen more accurately to make a better diagnosis and to plan surgery; to obtain more accurate pictures of a procedure during surgery; to perform a variety of non-invasive surgeries; and to model interactions among molecules at a molecular level.

This framework has come to rely upon the practice of so-called evidence-based medicine (EBM), which aims to assess medical treatments and technologies in order to standardise treatment and guide clinical practice. EBM is intended to be “both a critical summary of relevant research and the use of that evidence to make decisions about medical care” and used in “informing health policy, commissioning resources and directing clinical practice” (Rogers, 2004: p. 51). It has therefore promised “an objective and rational basis for healthcare” (Rogers, 2004: p. 51), with methods such as randomised controlled trials and systematic reviews.

Although this biomedical approach is the most common way for a condition like WCPP to be understood, it is by no means uncontested. Much of this critical attention has come from medical anthropologists and sociologists, who assume the social construction of medicine (i.e. — medicine does not exist ‘out there’ as a fact, waiting to be discovered, but rather, it is created and fashioned in a reciprocal manner by medical professionals and society) (Kleinman, 1999)). This critique often focuses on the problem of medicalisation, to be discussed later in this chapter. The sociological critique of biomedicine commonly identifies certain key features of the biomedical approach for criticism, namely that disease is understood as a deviation from ‘normal’ biological functioning, while the doctrine of specific aetiology is applied to all disease and understood to be generic or universal

in nature and medicine is considered scientifically neutral and objective (Mishler, 1989).

The discourses employed by biomedicine have also been highlighted as cause for concern. Greenhalgh (2001) has noted different discourses in routine use in biomedicine, and the deleterious implications of them. The discourse of objectification splits the patient into 'objective' body and 'subjective' mind/emotion; the discourse of quantification turns the patient's bodily signs and symptoms into a set of numbers so that the only information that counts is that which can be quantified; the discourse of pathologisation makes disease, not health, the object of attention, affixes disease labels; and, the discourse of amelioration downplays the issue of cause, focusing instead on treatment (p. 28). These discourses are politically relevant, as they are reinforcing power structures. Stone (2002) has discussed how quantification, for example, has political ramifications, because to quantify indicates that something is considered important enough to count, attempts to delineate the boundaries of an issue or create a community, and offers the promise of precision, accuracy and objectivity. To stay with this example, quantification also relies upon a decision maker who has the power to decide what will be counted and how.

Biomedicine has also been criticised for the perpetuation of 'myths' about medicine, including those of long standing, like that of scientific certainty, medical progress and heroic medicine, and those more recent, like infinite demand, the patient as consumer or partner, and the perfectibility of health, which "justify the high status of experts...and limit the part that outsiders can play in making choices for themselves as patients or questioning policies as citizens" and also "encourage us to equate health with health care" (Hogg, 1999: p. 173).

It is important to note that those disciplines commonly responsible for such criticisms, medical anthropology and sociology, have also been criticised for focussing too much on issues of illness behaviour and medicalisation, while overlooking the role played by health systems and services (Pierret, 1993) and failing to integrate biological understandings of the body and thus failing to represent the body faithfully and rendering it incomplete. This has been

described as resorting to a kind of ‘sociological reductionism’ (Bury, 1986), or ‘discourse determinism’ (Williams, 2006).

Understanding the biomedical model is essential to understanding the problem of WCPP and its place on the policy and public agendas, because issues like this are, almost inevitably, dealt with within this model by our society. The implications of this for WCPP as a potential agenda item will be explored in greater depth in the following chapter, but it is already clear that WCPP may be hindered by this focus on the biomedical, which values certain means of explanation and promotes expertise over experience.

### **The Public Health Model**

Despite its prominence, the biomedical approach is not the only way in which health and health care are addressed. The public health model is another way in which these issues may be addressed. Public health is normally directed towards non-personal health services and preventive services, and the term is often associated with the tackling of a ‘public health problem’, such as an epidemic (Hunter, 2003). The use of ‘public’ denotes both governmental action and the community (Hunter, 2003).

Public health, which is anticipatory by nature (Baggott, 2000) and traditionally concerned with raising the health of populations, has serious implications for the type of health care that is required. As Paton (1996) has outlined

“a society in which people ‘die earlier’ because of health-related behaviours may be a society that saves money on long term social care and social security budgets, as well as a society that raises revenue from, for example, the sale of cigarettes...(whereas) a society that successfully implements a broad public health strategy involving health promotion and health prevention, which feeds through to longer living for all, may well be a society that incurs greater ‘acute’ health care costs at the end of individuals’ life-cycles” (p. 5).



While this is not necessarily an inherently negative consequence, it is important to fully understand the shift that a public health perspective requires in all facets of policy.

Because of the dominance of the biomedical approach to health and illness, public health is potentially hamstrung by its inability to conform to the same standards as biomedicine. Evidence-based techniques, of the same nature as biomedicine relies upon, are much more difficult to use in public health, as interventions apply to wider populations and results occur over long periods of time (Hunter, 2003).

Public health is also heavily dependent on the practices and ideals of preventive health and health promotion. The WHO's 1986 Ottawa Charter for health promotion defined health promotion as "the process of enabling people to increase control over, and improve, their health". The charter prescribes five key actions: building Healthy Public Policy, creating supportive environments, developing personal skills, strengthening community action and reorienting the health services. The Bangkok Charter (WHO, 2005a) followed, to address the question of how health promotion should operate in a globalised world. The key commitments made were to make the promotion of health central to the global development agenda, a core responsibility for all of government, a key focus of communities and civil society and a requirement for good corporate practice.

Health promotion, therefore, is highly politicised. No doubt in part because of this, health promotion is one source of interest groups in health policy, along with public health professionals, government officials, business groups, and consumer groups (Signal, 1998).

### Healthy Public Policy

Healthy Public Policy (HPP), also called Health Public Policy and Health Promotion Policy, has been outlined by the WHO as a critical aspect of health promotion and the improvement of health outcomes. The Ottawa Charter defines HPP as "coordinated action that leads to health, income and social policies that foster greater equity" (p. 2). The aim is to place "health on the agenda of policy makers in all sectors and at all

levels, directing them to be aware of the health consequences of their decisions and to accept their responsibilities for health...to make the healthier choice the easier choice for policy makers as well” (p. 2). This was expanded upon in the 1988 Adelaide conference, which emphasises the creation of supportive environments to enable people to lead healthy lives, make healthy choices, and live in healthy social and physical environments.

HPP is not to be confused with health policy. Hancock (1985) has described public policy as focusing on the existing health care system, present health problems and dominated by the biomedical approach. HPP, instead, is future-oriented, focuses on multiple, local solutions to health problems that are more inclusive of the community, and tends to employ ‘soft’ technology. It may help to address issues like WCPP, which do not fit well into traditional health policy. The public health model itself may not be particularly well suited to an issue like WCPP, which cannot easily be dealt with as a population health issue, and which too little is known about for a preventive campaign to be run.

### **Environmental Health**

Environmental health can in many ways be understood as a part of public health, but it is much more limited in its focus. Environmental health is focussed on

“all the physical, chemical, and biological factors external to a person, and all the related factors impacting behaviours. It encompasses the assessment and control of those environmental factors that can potentially affect health. It is targeted towards preventing disease and creating health-supportive environments” (WHO, 2009).

The environmental health movement is thus typically concerned with issues like sanitation, water supply, radiation, air quality and food safety. Because the environmental health approach focuses on these types of issues, it tends to challenge the societal order and implicate structural and institutional factors as responsible for poor health outcomes, and is therefore highly politicised (Karpf, 1988).

The environmental health movement has also extended into issues usually considered from a biomedical perspective, including WCPP and especially endometriosis, which is thought to be linked to the toxin dioxin (Capek, 2000). However, this paradigm applies to such issues imperfectly, as it tends to focus on prevention (which does not help those already suffering from such conditions) and only accounts for environmental factors in illness.

### **Medicalisation**

The critique of medicalisation is most commonly applied to the biomedical model, but many of the concerns raised by this idea also apply to public and environmental health approaches, as will be discussed later in this chapter.

The term 'medicalisation' has been used in a number of different ways. Early analyses of medicalisation focussed upon the medicalisation of deviance (e.g. alcoholism, depression), but the term has also been applied to the increasing number of 'normal' life processes, or events falling under medical purview (e.g. ageing, impotence), as well as the creation of medical conditions from what might previously have been understood as variants of the human condition (e.g. Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome). In this way, medicalisation is commonly considered to result from advances in medicine (or the advancing abilities of medical science) and the growing demand of health consumers for the benefits arising from these advances (Conrad 2004; Zola, 2001 [1972]).

The connotations of medicalisation are often negative, particularly when the term is used to refer to the role of medicine as a means of social control (Foucault, 2003 [1963]). Thus medicalisation has also been seen as "a historically-specific social process whereby medical discourses play an important role in constructing culturally powerful significations of bodies and creating the institutional structures for medical regulation and intervention" (deRas and Grace, 1997: p. 9). Some authors therefore argue that the medical profession and system as "engaged in micropolitics at the site of the body" and as "complicit in supporting the hegemonic project of the state" (Nichter, 1998: p. 327).

Although there are varying conceptions of medicalisation, its complex nature and its existence as a *process* are rarely in question. Klawiter (2008a) and Williams (2003) have suggested that there are four levels at which medicalisation operates:

- i) conceptual level: when medical vocabulary or models are used to define a ‘problem’;
- ii) institutional level: when organisations use a medical approach to tackle or control a particular problem;
- iii) interactional level: when doctors and patients meet face-to-face in medical encounters and treatments are prescribed; and,
- iv) the individual level.

As already mentioned, medicalisation is understood as a process. Because of this, any discussion of medicalisation implies that there is some kind of *initiation* point. Illich (1976) suggested that

“until recently medicine attempted to enhance what occurs in nature. It fostered the tendency of wounds to heal, of blood to clot, and of bacteria to be overcome by natural immunity. Now medicine tries to engineer the dreams of reason...”(Illich, 1976: p. 47).

Foucault identifies this changing point as the turn of the eighteenth century:

“Generally speaking, it might be said that up to the end of the eighteenth century medicine related much more to health than to normality; it did not begin by analysing a ‘regular’ functioning of the organism and go on to seek where it had deviated, what it was disturbed by, and how it could be brought back into normal working order; it referred, rather, to qualities of vigour, suppleness, and fluidity, which were lost in illness and which it was the task of medicine to restore” (Foucault, 2003 [1963]: p. 40).

Conrad (2005) sees these changes as still occurring. He contends that medicalisation is continuing to advance, with the advance of genomic medicine, the rise of the pharmaceutical industry, the commodification of healthcare and the ascendance of managed care.

The market has also been considered an important agent of medicalisation (Conrad, 2004). The links between illness and capitalism have been variously conceived, but certainly capitalism “allows for the creation of new and highly profitable markets, and medicalisation has the potential for creating new markets through expanded definitions of social and personal problems” (Loustaunau and Sobo, 1997: p. 131). These markets create a kind of self-fulfilling prophecy, where health products (e.g. – pharmaceuticals) and health services are provided to meet demand, and demand continues to grow due to the seemingly endless advances of biomedicine.

Others have expressed concern that, in the attempt to emphasise the importance of the medicalisation thesis, and in introducing agents such as health consumers, the concept has been expanded too far. Whereas medicalisation was once understood in relatively narrow terms, concerns have been raised that the thesis has lost its emphasis on *medicine* and now only refers to “a medical approach to bodily conditions” (Purdy, 2001: p. 257), when this is in fact often based on *lay* understandings of medicine and is not being directed by the medical profession. This is seen to dilute the power of the argument (Davis, 2006). Some have gone so far as to question whether processes of medicalisation can even be fairly described as such. It is contended that the medical profession is far from united, and that there is no organised agenda to further the reach of medicine as is sometimes implied in the medicalisation thesis. Williams (2003) notes that “medicine itself is not composed of a body of like-minded individuals. Instead it is split into a variety of specialisms and factions, with much in-house fighting to boot” (Williams, 2003: p. 20). This diversity has been emphasised by Bransen (1992), who describes medicine as “a melting-pot of contradictory theories and practices, controversies and inexplicable phenomena, about which doctors and laypeople are in constant debate” (p. 99). Similarly, Doyal (1998) has noted that it is no longer appropriate (if it ever was) to categorise western medicine as a monolithic unified institution devoted only to hard science and high technology” (p. 15).

Bury (1982) has even warned that the medicalisation thesis, when taken to its extreme, is “sociologically naïve” (p. 179). He argues that, especially when facing terminal illness, patients *must* turn to biomedical approaches, and that the

medicalisation thesis implies that this is not a reasonably, or even morally acceptable response.

While these concerns certainly have merit, the institutional aspects of medicalisation must be acknowledged. It can be argued that because “the traditional conception of the goal of medicine is that medicine should treat disease...conditions recognised as important tend to be defined as diseases, promoting medicalisation” (Purdy, 2001: p. 248). The term can most usefully be understood as the process of “defining a problem in medical terms, or using a medical intervention to treat it” (Conrad, 2005, p. 3), or as “a specific social process – the expansion of the jurisdiction of the medical profession that followed from the successful redefinition of forms of deviance, natural life processes, and problems of living as illnesses requiring medical intervention” (Davis, 2006: p. 51).

Medicalisation is closely linked to the problem of risk; as a condition is medicalised, people are ‘at risk’ of having it. This illustrates the concept of ‘risk society’, outlined by Beck (1992), which describes a society organised in response to risk. Baggott (2000) is among those to note that risk identification itself may function as another tool of social control, and it is one way that medicalisation could be held to be potentially coercive. He suggests that there has been a shift from ‘dangerousness’ to ‘risk’, “shifting the focus of policy away from individuals manifesting signs and symptoms of impending illness, abnormality or social deviance, towards anticipating and preventing problems” (p. 11) and providing the basis for differential treatment of populations. Risk is self-perpetuating; increasing *knowledge* of risk means more *sense* of risk, and this is one way in which medical authority has been maintained over time (Belgrave, 2008). Illich (1976) has warned that “once a society is so organised that medicine can transform people into patients because they are unborn, newborn, menopausal, or at some other ‘age of risk’, the population inevitably loses some of its autonomy to its healers” (p. 86).

It should be emphasised that there are benefits of medicalisation, as is implied by lay efforts to accelerate this process, which will be discussed later in this chapter. Medicalisation may enable a problem to be funded and researched, and result in improved quality of life: a problem may be alleviated by medical treatment; stigma

may be reduced, and the individual may have their experience legitimated, therefore enabling access to social and financial resources of support (Conrad, 2007; Lorber, 1997; Broom and Woodward, 1996). It has also been suggested that medicalisation, with its adherence to the biomedical model, may reassure patients who feel overwhelmed by uncertainty and ambiguity, as it casts the patient's experience within certain terms that potentially clarify treatment paths and outcomes (Abel & Browner, 1998). Therefore the process should not be understood as inherently negative; nor should its benefits in a case like WCPP be overlooked.

Despite this, concerns remain about the negative impact of medicalisation. Zola (2001 [1972]) has warned against the belief in the "omnipresence of disorder" and corresponding belief in the ability for even health to be enhanced that he identifies. He warns that, by treating a human condition as an illness, it predetermines the response to this condition:

"By locating the source and the treatment of problems in an individual, other levels of intervention are effectively closed. By the very acceptance of a specific behaviour as an 'illness' and the definition of illness as an undesirable state, the issue becomes not whether to deal with a particular problem, but *how* and *when*" (p. 411).

Zola also warns against the sensation that "virtually anything can lead to certain medical problems...living is injurious to health...every aspect of our daily life has in it elements of risk to health" (p. 410) that medicalisation creates. Conrad (2007) has termed this the 'pathologisation of everything', which occurs when "virtually any human difference is susceptible to being considered a form of pathology, a diagnosable disorder, and subject to medical interventions" (p. 148).

Similarly, Broom and Woodward (1996) have warned that "medicine cannot overcome all human distress, and that labelling life experiences or social problems as 'diseases' subjects them to medical control without necessarily conferring any curative or palliative benefits" (p. 360). Along with Conrad (2007), these authors express concern that illness, when medicalised, becomes an *individual* matter, where social context is overlooked, and community and state are excluded.

The advent of chronic illness as a recognised health issue intensifies these concerns. Greenhalgh (2001) suggests that:

“Although the treatment of chronic pain is one of scientific medicine’s most visible failures, in a time of shrinking resources, medical specialists are only too happy to have a new domain in which to apply their skills. Research scientists develop diagnostic criteria for a new syndrome, clinical scientist work out treatment protocols, and a new group of specialists emerges with a guaranteed stable of patients for life. Before long, a bona fide new disease has entered the medical and cultural mainstream” (p. 3).

Another concern arises when, in a medicalised world, a condition is not sufficiently or successfully medicalised, such as has been argued to have occurred with conditions such as Gulf War Syndrome (Charmaz, 1999) or Multiple Chemical Sensitivity (Dumit, 2005). The perceived danger is that conditions such as these will be overlooked in a society where a condition has to have been incorporated into the biomedical model to be considered legitimate. A related problem, highlighted by Clarke et al. (2003) with regard to biomedicalisation, is that the process is not an *even* one, but rather, is stratified: it affects some members of society more than others. This widens the gap between what Clarke et al. (2003) describe as the biomedical ‘haves’ and ‘have nots’.

It is evident, then, that the concerns about medicalisation are wide-ranging and profound. What is clear is that medicalisation cannot be understood in simplistic terms: it is not a phenomenon that can be considered positive or negative simply in itself.

#### Lay-led medicalisation

Similarly, medicalisation is not always a ‘top-down’ process. As has already been noted, members of the medical profession are not the only agents of medicalisation. Conrad (2005) has suggested that social movements and interest groups may also drive medicalisation, and, patients and the wider lay community must also be considered. Patients may adhere strictly to biomedical explanations when they are



seen as legitimising their illness experience (Dumit, 2005). They may also participate in the construction of the dominance of biomedicine; Oianas' 1998 study of doctors' advice to adolescent girls in medical advisory columns indicates that young women perceive the doctor as the expert regarding the body, and turn to the doctor for definitive answers about their experiences.

Nichter (1998) argues for the importance of the social context of medicalisation, describing processes of what he calls 'self-initiated medicalisation', referring to patients' use of medical terms to talk about their illness experience. He suggests that some patients may self-initiate medicalisation, in order to help them cope, explain their experience to others, and to permit time and space in which to adjust to illness conditions.

It has also been suggested that these apparent instances of lay-led medicalisation have in fact been misinterpreted. It could also be that patients are simply using those terms with which they are already familiar, because of society's wide acceptance and common use of them. Peters et al. (1998) have suggested that medical terms are adapted to express pre-existing beliefs, rather than being 'owned' by patients in any way.

### Biomedicalisation

The term 'biomedicalisation' has been coined by Clarke et al. (2003) to herald what they identify as the dawn of a new era of medicalisation, brought about by technoscientific advances in biomedicine. These authors have defined biomedicalisation as

*“the increasingly complex, multisited, multidirectional processes of medicalisation that are today being both extended and reconstituted through the emergent social forms and practices of a highly and increasingly technoscientific biomedicine. We signal with the ‘bio’ in biomedicalisation the transformations of both the human and nonhuman made possible by such technoscientific innovations as molecular biology, biotechnologies, genomisation, transplant medicine, and new medical technologies. That is,*

medicalisation is intensifying, but in new and complex, usually technoscientific, ways” (p. 162, *italics added*).

These authors identify a clear transformation as having occurred in the medicalisation process, due to “improved access to knowledge, self-surveillance, prevention, risk assessment, the treatment of risk, and the consumption of appropriate self-help/biomedical good and services” (p. 162) and the new responsibilities this brings the individual. This can be explained partly by the new focus on the internal: “the shift to biomedicalisation is a shift from enhanced control over external nature (i.e., the world around us) to the harnessing and transformation of internal nature” (p. 164). Information and communication technologies also enable the greater reach of biomedicalisation. Klawiter (2008b) has suggested that although medicalisation and biomedicalisation may overlap, the latter is important, as together they have a cumulative effect.

This view of biomedicalisation relies upon a particular understanding of biomedicine, one that is not analytically distinct from science. It has been suggested that the two should be considered separately, as the methods and nature of each are quite different, although admittedly with marked points of similarity (Whelan, 2009; Hafferty, 2006).

#### The medicalisation of women’s bodies

It has been suggested that medicalisation is particularly prominent in women’s health, where normal events in women’s lives (e.g. ~~menarche~~, menstruation, pregnancy and menopause) and natural states (e.g. ~~small breast size~~) are constructed as pathological and requiring medical attention (Purdy, 2001). Dell (2000) has described how even women who have undergone hysterectomy have come to be classed as a syndrome, as ‘hysterectomised’. Riessman (2003 [1998]) argues that this tendency for women’s bodies to be medicalised is due to the fit between women’s biology and medicine’s biomedical orientation; women’s social roles, which make them readily available to medical scrutiny; greater exposure to medical labelling (due to experiences such as childbirth); and, women’s structural subordination to men (Riessman, 2003 [1998]).

As has already been noted with regard to medicalisation more generally, it should not be *assumed* that medicalisation is harmful to women. As Riessman puts it, “the medicalisation of human problems is a contradictory reality for women. It is part of the problem and part of the solution” (p. 59). However, the concerns identified may be intensified in relation to women’s health issues, as women have historically been discriminated against in the medical realm (Parsons, 2004). Many of these medicalised aspects of women’s health will be examined in greater detail in the following chapter.

Greenhalgh (2001) suggests that the medicalisation of chronic pain may be particularly unhelpful to women as it

“places women within a masculinist biomedical order in which the patient’s knowledge of her body and life is silenced in discourses of objectification that make the doctor the expert on the patient’s body...(and) exposes them to a sexual politics in the clinical encounter in which their dual subordination in the hierarchies of gender and science places them at risk of verbal and emotional abuse” (p. 320).

In order to illustrate the way in which medicalisation operates with regard to women’s bodies, it is useful at this point to consider the example of breastfeeding. Ryan and Grace (2001a) trace the process of the medicalisation of breastfeeding in New Zealand over the course of the twentieth century, identifying the beginnings of this in the monitoring of women’s bodies during childbirth in the inter-war period, and subsiding with the women’s movement and new emphasis on a women’s rights over her own body in the 1960’s and 1970’s. They note how breastfeeding has been *remedicalised*, at the expense of experiential and shared knowledge. So unquestioned is the medicalisation of breastfeeding that a health education/promotion programme is currently operating in New Zealand that advocates the health benefits of breastfeeding for infants, evidence of the ways this life process (and individual choice) has been medicalised.

### Public health and medicalisation

The issue of medicalisation does not apply only to the biomedical model of health and illness. Similar concerns have also been raised with regard to public health,

particularly health promotion, which has been criticised for being coercive, paternalistic and idealistic. Zola (2001 [1972]) warned of the dangers a well intentioned and seemingly benign ideal of health, like those in preventive medicine and health promotion, might do, writing that medicine is a

“battleground, not because there are visible threats and oppressors, but because they are almost invisible; not because the perspective, tools and practitioners of medicine and the other helping professions are evil, but because they are not. It is so frightening because there are elements here of the banality of evil...here the danger is greater, for not only is the process masked as a technical, scientific, objective one, but one done for our own good” (p. 412).

It has been argued that preventive medicine presents these dangers.

These concerns often arise because of the burden these models are thought to place on the individual, which, it should be noted, are contradictory to the aims of public health (as it aims to focus on population-level health) and is particularly unhelpful at a time when individuals have, in many ways, less control than ever before over the circumstances of their own health (Lupton, 2001; Minkler, 1999; Verweij, 1999). This concern is well illustrated by the problem of WCPP, which cannot be demonstrated to be tied to individual behaviour.

Lupton (2003, 2001) has explored these concerns, discussing risk discourse and the construction of the body in public health and the ways in which these act in a disciplinary way. She notes the tendency for public health to regard the body as “dangerous, problematic, ever-threatening to run out of control, to attract disease” (2003: p. 27). She has suggested that typical public health activities, such as health promotion, health education, fitness testing and mass screening are inherently disciplinary by nature, but that this is obscured by the rhetoric of public health discourse, which deems health a universal right and fundamental good. She has also noted the role of risk discourse in public health, identifying the dual nature of risk in public health, that of environmental hazards and that of the consequences of lifestyle choices (2001). With regard to environmental hazards, the sense of risk is externalised, and the common response is that of helplessness, anxiety and perhaps anger, whereas in the case of lifestyle choices, the emphasis comes to be placed on

individual self-control. As Belgrave (2008) has noted, the focus on lifestyle may be a way for the state to escape responsibility for the social gradient in health outcomes, as it places the responsibility for health firmly on the individual. It is this focus on the individual that Lupton suggests is disciplinary, and she suggests that health promotion that emphasises risk is a “form of pedagogy, which...serves to legitimise ideologies and social practices...(and) allows the state, as the owner of knowledge, to exert power over the bodies of its citizens” (2001: p. 400).

This sense of risk suggests that public health, particularly health promotion, contributes to the creation of the ‘worried well’, just as biomedicine does. Williams (2003) has suggested that “(w)hether through advice books or psychotherapy, emotion work or bodily maintenance, health promotion or predictive medicine, television or telemedicine, our bodies and selves are continually called into question” (p. 108). Certainly health promotion, despite its ambitions, tends to be ‘top-down’ in its approach, which is not only prescriptive, but potentially coercive (Karpf, 1988).

Armstrong (1995) has argued that the late twentieth century has seen the rise of a new type of medicine, which he terms ‘Surveillance Medicine’, in which he sees as a “fundamental remapping of the spaces of illness” (p. 395). Surveillance Medicine is named for both its nature and its measures; it targets everyone, and is characterised by screening measures, emphasising pathologisation and vigilance (Armstrong, 1995). This has the effect of making health and the world seem precarious and risky. The very concept of ‘normal’ is problematic, and health status is conceived of as existing along a continuum, in order to make everyone subject to this surveillance. This also means that the “healthy can become healthier, and health can co-exist with illness” (p. 400). In these ways, health promotion tends to turn “life into a series of periods of risk, each calling for tutelage of a special kind...Life is thus reduced to a ‘span’, to a statistical phenomenon which, for better or worse, must be institutionally planned and shaped” (Illich, 1976: pp. 86-87).

The concept of Surveillance Medicine basically ascribes medicalising and disciplinary potential to preventive health. Because preventive health is naturally and inevitably concerned with healthy people, these are justifiable concerns. Verweij (1999) discusses these dangers in relation to preventive medicine. He describes how

preventive health measures are intended to “stimulate healthy people to think, wonder and worry about the possibility that they may become ill” (p. 96) and how health is presented in this framework as a “fragile equilibrium and as if human beings must constantly anticipate threats against their health” (p. 97). Preventive health may also be understood as coercive in that it gives the sense that there is only one right way to live, as it “publicly confirms and sustains views of life in which health is most important, and that, consequently, it becomes more difficult for individuals to live a life and embrace a view of life in which other values than health are most important” (p. 105). Individuals are effectively coerced to comply with preventive health principles and directives, on grounds that if they fail to do so they may be putting others at direct risk (e.g. + contagious disease); they may be restricting themselves in terms of other obligations, such as caring for others; (women) may be pregnant or intending to be; and, there may be a financial cost to others. In terms of WCPP, this may mean that women are ‘forced’ into treatments that they consider undesirable in order to comply with social mores.

One counter claim to this has been articulated by Hafferty (2006), who suggests that the result of all of this activity is not so much to increase people’s sensitivity to risk, but rather to *desensitise* them. He claims that although “we are bombarded with widely published and easily accessed morbidity and mortality statistics, yet we expect the downsides of our denial to befall ‘the other guy’” (p. 45). Of course, this may be every bit as dangerous, and in terms of agenda setting, may result in apathy.

### Demedicalisation

It should also be mentioned that, although it is generally identified that the medicalisation trend is continuing (perhaps, even, morphing into something better described as *biomedicalisation*), there are also instances of the reversal of the process. Demedicalisation has occurred where medical or scientific evidence has been presented to demonstrate that an issue does not belong in the medical realm, when societal norms have removed an issue from the medical realm (e.g. – homosexuality), and perhaps also in instances when medicine has been unsuccessful in addressing a problem (e.g. – criminality). This usually only happens after the concerted efforts of an interest group (Davis, 2006).

Certainly as patients acquire more information, they are more likely to realise the lack of unanimity among biomedical or public health practitioners, and these “fissures in medical expertise provide opportunities for women to rely on their own experiential knowledge” (Abel & Browner, 1998: p. 332).

## **Conclusion**

Whatever conclusion is drawn about the nature of medicalisation, the debate itself has been useful and served as a valuable check against the power of the medical profession. As Williams (2003) notes, the medicalisation thesis raises a number of important questions, better investigated and resolved than overlooked. It also serves to emphasise the ways in which medicine (and its dominance) has social implications and the ways in which it might be socially constructed (Riessman, 2003 [1998]).

Understanding these concerns, and the frameworks in which issues of health and illness are regarded, is central to a consideration of WCPP in the New Zealand health system and agenda-setting processes. The following chapter will examine more closely why these frameworks are insufficient in providing WCPP with the foundation to enable a place on the policy or public agenda.

## **CHAPTER THREE**

### **WOMEN'S CHRONIC PELVIC PAIN**

#### **Introduction**

This chapter will discuss the place of WCPP on the public and policy agendas in New Zealand, and go on to consider the reasons behind this. It is suggested that this particular health issue fails to map onto any of the frameworks outlined in the previous chapter, and so tends to lack explanatory power and political force.

It is useful to clarify the use of terms. Chronic diseases are often described as 'non-communicable' or 'lifestyle' diseases. Both of these terms are misleading. Some chronic diseases have an infectious component, and lifestyle may play a role in communicable as well as non-communicable disease. The use of the 'lifestyle' label has also been avoided because it implies the individual's responsibility for their disease, as discussed in the previous chapter. Furthermore, the term 'disease' implies a focus only on physiological aspects of illness, while the term 'chronic illness' suggests a focus purely on the individual's sickness. The term 'chronic condition' is preferred in order to encapsulate that diseases have biological, social, psychological, cultural and economic elements; that is, disease is experienced by individuals to produce a condition.

#### **The place of WCPP on the agenda**

While women's experience of chronic pelvic pain varies considerably, a useful definition is: "lower abdominal pain located in the pelvis, which is not specifically related to the menstrual cycle, and which has a duration of longer than six months" (Pitts, McGowan & Carter, 2000: p. 244). The separation of WCPP from menstruation is particularly important; WCPP is clearly 'more than' menstrual problems or dysmenorrhoea (period pain) (Zondervan et al., 2001a). However, menstrual problems, dysmenorrhoea and dyspareunia should be included in considerations of WCPP, as these can contribute to the experience of this condition. Uncertainty surrounding the definition has hampered research efforts, particularly epidemiological efforts on incidence (Zondervan, 2000). Chronic pelvic pain is commonly attributed



to gynaecological conditions such as endometriosis, adenomyosis, pelvic congestion syndrome, pelvic inflammatory disease, or fibroids, but may also have gastrointestinal, urological or musculoskeletal origins (ACOG, 2008).

As mentioned in Chapter 1, a New Zealand population-based study in 2001 found the community three-month prevalence of WCPP to be 25.4% (Grace & Zondervan, 2004). The three-month prevalence of dysmenorrhoea among women who had had periods in the last 12 months was 55.2% and the 12-month prevalence was 66.5%. Only 34.2% of women surveyed reported no chronic pelvic pain, dysmenorrhoea or dyspareunia in the last 12 months (Grace & Zondervan, 2004). These figures are similar to those in the United Kingdom, where the three-month prevalence of WCPP has been reported to be 24% (Zondervan et al., 2001b), but dysmenorrhoea and dyspareunia are reportedly higher in the United Kingdom, at 81% and 41% respectively (Zondervan et al., 2001b). These figures appear higher than the American figures, which state the prevalence of WCPP at 14.7% (Mathias, et al., 1996). This difference can be accounted for by the fact that the American study did not include mid-cycle pain.

Despite the prevalence of WCPP, the issue barely features on the policy agenda in New Zealand. The prevalence of WCPP in New Zealand is comparable to chronic health conditions as reported by the NHC such as neck and back pain (one in four adults), asthma (one in five adults aged 15-44), mental illness (one in five adults) and significantly higher than others, such as heart disease (one in ten adults) (NHC, 2007) that get a great deal of attention from researchers, policymakers, and the public, and yet is not mentioned in their report *Meeting the needs of people with chronic conditions*. A number of national strategies in New Zealand can be linked with reducing the incidence and burden of chronic disease, such as the New Zealand Health Strategy and Healthy Eating-Healthy Action (HEHA) Strategy, which emphasises the reduction risk factors; He Korowai Oranga (Maori Health Strategy), the Pacific Health and Disability Action Plan, the Health of Older People Strategy and the New Zealand Disability Strategy, all of which focus on particular groups disproportionately affected by chronic conditions; and the Primary Health Care Strategy, which has attempted to introduce better awareness of wider determinants of health and aims to reduce inequalities within a population health framework.

However, these strategies do not directly address the problem of WCPP, nor do they account for the particular issues that chronic pelvic pain poses. Most surprisingly perhaps, the 2001 Sexual and Reproductive Health Strategy fails to mention chronic pelvic pain, which has clear links to reproductive health. This demonstrates that the problem of WCPP does not feature on the policy agenda in New Zealand.

There is evidence to suggest, however, that WCPP is beginning to feature on the public agenda. There are a number of different support groups and websites dedicated to this issue. Unfortunately, this seems to be coalescing around endometriosis, only one potential cause of WCPP. Although limited to this condition, these are promising signs. Endometriosis Awareness Week (March 2-8) was marked for the first time in New Zealand in 2009 (Endometriosis Waikato, 2009). The New Zealand Endometriosis Foundation (ENZ), based in Christchurch, works to raise awareness of endometriosis, support and advocate for women, and runs a community education programme for girls through Canterbury's secondary schools (Endometriosis New Zealand, 2009). This organisation has been forced to rely on funding from community organisations, such as The Community Trust (Community Trust, 2002) and The Lottery Grants Board (N.Z. Lottery Grants Board, 2006).

The question very quickly becomes, then, why the issue of WCPP is not better recognised at a policy level.

#### Failure to fit into biomedical model

Perhaps the most obvious explanation is the failure of WCPP to fit easily into the dominant biomedical model. Health policy remains heavily influenced by biomedical tenets, and the inability of WCPP to be explained in these terms renders it a problematic potential agenda item.

In Grace and Zondervan's 2004 study of WCPP in New Zealand, it was found that 47.7% of women with chronic pelvic pain remained undiagnosed (Grace & Zondervan, 2004), while the American figure is thought to be even higher (Mathias et al., 1996). For many of these women, a satisfactory explanation for their pain may never be found. (The problem of diagnostic delay with regard to specific conditions is

clearly illustrated in the case of endometriosis, and will be discussed further in the next chapter.)

In the biomedical model, diagnosis is an extremely important step, one essential to recovery, as diagnosis is posited as preceding successful treatment. Ballard, Lowton and Wright (2006b) have described the importance of a diagnosis also for women suffering from endometriosis. Diagnosis was found to provide

“relief through providing a language to talk about symptoms, which in turn sanctioned access to social support and the potential for appropriate treatment strategies. Further relief arose from finding that they did not have a more sinister problem, such as cancer” (p. 1299).

It is also noted that there may be less commonly considered effects of a diagnosis:

“women were offered hope for appropriate treatment, providing a sense of control over their condition and a relatively long-term management strategy” (pp. 1299-1300).

Such benefits have to be considered against potential losses, particularly a loss of privacy (Gilmour, Huntington & Wilson, 2008). A diagnosis may also mark the award of credibility or legitimacy (Thorne, 1993). Bury (1991) describes how this may be challenged, “if the individual continues to report problems after their ‘share’ of attention has been used up, or when they have been placed in a category (e.g. – ‘successful operation’) which closes off avenues of support and information” (p. 457), resulting in what he describes as a ‘credibility crisis’. This is even more pronounced when a diagnosis cannot be found, as is often the case with WCPP. In some instances, extensive tests may be undertaken to discover organic pathology, without any being found and this may become an excuse for removing WCPP from medical purview, thus extinguishing the medical practitioner’s responsibility to relieve symptoms (Grace, 2001a, 2001b). While biomedical practitioners may claim that the ‘medically unexplained’ label is neutral, it has negative connotations for patients, and implies that biomedicine may thereafter ignore them (Stone et al., 2002).

Greenhalgh (2001) has argued that the diagnosis should not be so valued in biomedicine, because it has a ‘labelling effect’, and it becomes

“hard to resist metamorphosing into our labels, letting what is known about the disease, its symptoms, and likely course infiltrate our sense of who we are and can be. As pharmacological treatment proceeds, our bodies are biochemically altered to ‘match’ our new identities.” (p. 307).

This may be the case in WCPP also, especially with regard to hormonal treatments, which are often reported to have a negative effect on women’s sense of wellbeing (Trickey & Cooke, 2000).

As Whelan (2003) explains with regard to endometriosis, the patient is forced to rely upon diagnosis, as the patient

“can only assert an exclusive communal knowledge of ‘endometriosis pain’ because of medicine’s naming of endometriosis as a diagnostic category; individual women can only apply the label of endometriosis pain to their pain once they have received a diagnosis from a medical expert. As such, the endometriosis patient community’s common objects, its individual membership, indeed its very existence, depend upon medical definitions and claims” (p. 477).

WCPP is not easily diagnosed: as already mentioned, it may be due to many different causes, and often, organic pathology will not be found (Grace, 1998). Grace (2000) has suggested a continuum of credibility in WCPP, from the identification of a definite gynaecological cause (most credible) to a definite non-gynaecological cause, to non-organic disease but evidence of an affective disorder, to no evidence of organic pathology or psychiatric distress (least credible). WCPP may be described as a condition of low specificity with an absence of clear aetiology, progression and distinct interventions, which serves to make it difficult to treat in a biomedical sense, or even consider within the biomedical model (Royer, 1998). Although the advent of laparoscopic surgery since the 1970s has meant more diagnosis of underlying pathology, there remain many women unable to find a biomedical explanation for their pain (Pitts et al., 2000) or biomedical (pharmacological, hormonal or surgical) interventions that are effective in reducing pain (Andersson & Hovellius, 2005).

Kleinman et al. (1994) have described chronic pain as having an anomalous status in biomedicine because the pain cannot be accounted for in its own terms. This

“renders pain a quintessentially anomic condition: no coherent system of values and beliefs emerges from the pain experience or survives its morally corrosive effects...Pain is an inner experience, and even those closest to the patient cannot truly observe its progress or share in its suffering”(Kleinman et al., 1994: p. 5).

This suggests another reason that WCPP does not feature on the policy agenda: the failure to map onto a model of pain.

#### *Failure to map onto a pain model*

Pain is a complex phenomenon that is itself not well treated by biomedicine, nor well managed in society (Apkarian, Baliki & Geha, 2009). This again means that the condition cannot be sufficiently well explained to become a viable agenda item. It has been defined by the International Association for the Study of Pain (IASP) (2009) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. There are two basic views of pain underlying biomedical approaches: that pain is “a component of the sensory repertoire of most animals that warns us of impending damage, gives accurate information to the brain about injuries and helps us to heal”, or, the view that “attaches to both pain, and its opposite pleasure, fundamental roles in shaping the emotions and behaviours of the individual...(In this view), pain is seen as a trigger of emotional states, a behavioural drive, and a highly effective learning tool” (Cervero, 2009: p. 5). In this latter view, pain may also be seen as a ‘teacher’ or guide (Vertosick, 2000). Which of these basic assumptions is used is important because it determines what is to be studied: if the former assumption, then the study of sensors, if the latter, then patterns of activation (Cervero, 2009).

While it is not commonly thought of as such, pain may function as a political issue. Scarry (1985) has suggested that pain is inherently political because it is about *power*. She explains that this has four dimensions: a person can be in pain without another

being aware of it, thus placing one in a position of power over the other; pain cannot be easily politically represented, as it resists verbal objectification (this is the crucial problem in terms of agenda setting, as identified above); some means of verbalisation can be invoked to inflict further pain; and, pain cannot be denied or confirmed, someone has to decide, placing them in a position of power over others (Scarry, 1985).

Loeser (1975) has provided a much-used taxonomy of pain, which consists of different levels of pain. Loeser and Melzack (1999) have provided a clarified outline of this, which notes the components of pain as nociception, the detection of tissue damage; the perception of pain, frequently triggered by noxious stimulants, or generated by lesions; suffering, the negative response induced by pain and other psychological states; and, pain behaviour, the things people do or do not do that can be ascribed to tissue damage. Already, it can be seen that a condition like WCPP is unlikely to fit into this kind of model, where there is often no discernible tissue damage. This potentially calls into question the entire nature of this condition, rendering it inexplicable in these models of pain.

Perhaps the most important advance in understanding pain has been the gate control theory advanced by Melzack and Wall (1965). This opened up new possibilities: it drew attention to pain *modulation*, thus highlighting the shortcomings of previous theories of pain based on the notion of pain as a sort of sensory ‘alarm system’ (Cezero, 2009). Since this development, it has been identified that there are a number of different *types* of pain (e.g. – traumatic, inflammatory, neuropathic, etc.), and pain is often described as being acute *or* chronic, benign *or* cancerous and real *or* psychogenic (Seitz, 1993). The IASP has also proposed a coding scheme, which considers the region of pain, the organ systems involved, the temporal characteristics and patterns of occurrence, the patient’s statement of intensity and duration and presumed aetiology (as cited in Seitz, 1993).

Pain research is currently advancing very quickly, particularly in the area of neurobiology, where the role of nociceptors (also called pain receptors), the nature of neural plasticity in adults, and the importance of descending modulatory systems in the response of the nervous system are becoming clearer, and imaging studies have

shown the distribution of pain information across multiple forebrain sites involved in attention, motivation and cognition (Apkarian et al., 2005; Dubner & Gold, 1999). This research provides hope that these physiological and neurological aspects of pain will be better understood in the near future, and that this understanding will give rise to alleviation of suffering.

It is also suggested that pain cannot be understood solely from a biological perspective. The kinds of models described thus far tend to be primarily biomedical in their focus, and have been criticised for reducing “the experience of pain to an elaborate broadcasting system of signals, rather than seeing it as moulded and shaped both by the individual and their particular socio-cultural context” (Bendelow & Williams, 1995: p. 140). They can also be seen as insufficient in explaining the nature of pain in a condition like WCPP. In an alternative formulation, pain is an *experienced* phenomenon and is always subjective (IASP, 2009). Pain perception may be influenced by a number of psychological, social, personal and cultural factors.

Vrancken (1989) outlines the different approaches that have been taken to pain in this sense, describing them as somatico-technical, dualistic body-oriented, behaviourist, phenomenological and consciousness. The somatico-technical approach is characterised by a pragmatic approach to pain, uses a neurophysiological model of pain, divides pain patients into patients with real pain, psychiatric patients and malingerers, and sees therapy as preferably causal (i.e. – prefers surgery). The dualistic body-oriented approach sees pain as the result of organic and psychological (and sometimes social) factors, and modulated by emotional, motivational and cognitive factors. Therapy is still causally based, but a combined organic-psychic approach is preferred. The behaviourist approach, understands pain as entirely subjective but able to be explained in neurophysiological terms in acute pain, or environmental and personality terms in chronic pain. It characterises pain patients as interested in complaining about pain or those whose coping behaviours have failed, and sees the object of therapy as minimising pain behaviours. The phenomenological approach considers pain an experience and characterises pain patients as those with a complaint against life. The object of therapy in this approach is thus

returning the patient to their life. In the consciousness approach, pain is thought to be a problem of consciousness. Thus it only really acknowledges chronic pain patients, and sees the purpose of therapy as to provide the conditions for the patient to recover. Vrankcen characterises the phenomenological and consciousness approaches as anthropological; they address our natural impulse to react to pain.

Others, however, have suggested that just because pain is subjective does not necessarily mean that it is also *unknowable*, but rather, that its inaccessibility to researchers is only because we have not yet found a way to assess it objectively (Devor, 2009). The objective assessment of pain is attempted through pain measurement techniques, and may be important for a number of reasons: to provide quantitative measures of patient function, monitor changes in clinical status, guide management decisions, evaluate treatment efficacy, prevent additional disability, predict prognosis, estimate care requirements and even determine compensation (Roth, 1990).

Techniques may focus on different aspects of pain, such as perception, appraisal, behaviours or impact (Dworkin and Whitney, 1992) and different instruments may be used to measure pain, such as interviews (e.g. – pain assessment report), self-report measures (e.g. – West Haven-Yale Multidimensional Pain Inventory, Pain Disability Index and Sickness Impact Profile), diaries, or combinations thereof (e.g. – McGill Comprehensive Pain Questionnaire) (Kerns & Jacob, 1992). Interviews and diaries are sometimes used in order to try to overcome the problems of quantification and categorisation presented by some of the other models (Horn & Munafò, 1997). Self-report measures, while economical and allowing the assessment of a wider range of factors, are often criticised, as patients may overestimate their pain retrospectively, and present pain levels are thought to influence the reporting of previous pain (Turk & Melzack, 1992). Different methods can also be taken to the sampling and recording of pain behaviours, including continuous observation, duration measure, frequency counts, time sampling, or interval recording (Keefe & Williams, 1992).



Keefe and Williams (1992) note that assessing pain behaviour is not straightforward, as what constitutes pain behaviour is not clear; inactivity itself, for instance could be considered pain behaviour, but is not necessarily so. There is also the problem of observer-bias, or counter-transference. The reliability of a pain measurement tool may be assessed by considering how successfully it assesses current status, contributes to a useful diagnosis, yields rational treatment decisions and evaluates the course of a pain condition over time (Dworkin & Williams, 1992).

### *Chronic Pain*

Pain that is ongoing adds another, complicating, dimension to the pain problem. Its very existence is counter-intuitive; one might expect that humans would adapt to pain, but instead, sensitisation often increases over time (Cervero, 2009). Chronic pain has been described as “any continuing pain that has lost its biological function” (Jackson, 1994a: p. 140). As Aronoff & Feldman (2000) have noted, when “pain becomes intractable, the entire hierarchy of the health care profession becomes compromised” (p. 157).

Bullington (2009) has suggested that chronic pain is an entirely different experience from that of acute pain, as the sufferer’s world changes in chronic pain. By this, she means that the “experience of pain transforms the world...It is not only the body which is disturbed by chronic pain, but the way the body can live the world” (p. 106). This commonly results in an alienation from others, as well as from the pre-pain self, as “(o)ne becomes pain” (p. 107). In this way, pain is “not merely a question of adverse sensations in the body...(but) a way of thinking, a way of feeling, a way of perceiving, a way of experiencing and a way of acting” (p. 104).

Certainly the impact of WCPP is not felt solely in terms of physical symptoms; as Moss and Dyck (2002) explain, women may feel marginalised by society as their identity, sexuality and productivity come into question and their condition is socially constructed as ‘illness’, with its connotations of “ignominy, lack, disapproval” (p. 17). The issue is also not solely individual; Rolland (1988) describes how chronic conditions affect families, who may be faced with a

period of “forced transition” (p.67), as there are often times of great upheaval and it is possible that the condition may “become unnecessarily embedded in family life or inappropriately ignored” (p. 64). Furthermore, it has been found that those experiencing chronic pain also tend to be more likely to have additional clinical and social problems, including unemployment or underemployment, marital and family dysfunction, alcohol and substance abuse, and general decline in social and recreational functioning (Kerns & Jacob, 1992). Bury (1982) has argued that chronic illness involves what he terms ‘biographical disruption’, of taken-for-granted assumptions and behaviours, of explanatory systems, so that a fundamental rethinking of biography (self) is needed, and of that caused by the mobilisation of resources against chronic illness (Bury, 1982). He describes how it is

“precisely that form of experience where the structures of everyday life and the forms of knowledge which underpin them are disrupted. Chronic illness involves a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others. In addition, it brings individuals, their families, and wider social networks face to face with the character of their relationships in stark form, disrupting normal rules of reciprocity and mutual support” (p. 169).

Chronic pain is thus a different experience to acute pain. This has given rise to concepts such as that of Chronic Pain Syndrome (CPS) (Aronoff & Feldman, 2000), which is “a descriptive term for individuals who exhibit persistent pain, poor coping, self-limitations in functional activities, significant life disruption, and dysfunctional pain behaviour” (p. 158), and links chronic pain to psychiatric disorders such as somatoform disorders; pain disorders; psychological factors affecting physical condition, such as migraine, dysmenorrhoea and sacroiliac pain; malingering; mood disorders, such as depression; and, personality disorders, especially passive-dependent, histrionic and antisocial personality; strong disability conviction and certain cognitive beliefs, e.g. – that rest is the appropriate response to pain. Previous experience of sexual abuse is also often linked to chronic pain syndromes (Carette, 1996; Radomsky, 1995). This is similar to the Learned Pain Syndrome (Brena & Chapman, 1985) which is characterised by the ‘Five D’s’: dramatisation of complaints, disuse, drug misuse, dependency and disability. There are also similarities

to the idea of a 'pain-prone personality' (Engel, 1958) which is characterised by an ambiguous attitude to pain, and is supposedly discernible by childhood needs, in which pain is linked to be soothed by the mother; punishment by parents, in which pain relieves guilt and produces expiation forgiveness and reunion; aggression and power in childhood where self-inflicted pain is seen as a form of control over aggression; the loss of a loved one; or pain enjoyed in a sexual context. These sorts of ideas work against sufferers of chronic conditions, as it is easy for them to be classed as having a syndrome of this nature, rather than suffering of any 'real' kind.

It is important to remember that many of these suggestions rest on unqualified assumptions. The charge of malingering, for instance, may be countered by the fact that many sufferers of chronic pain in fact view work positively, as a haven or escape from pain; an arena for self-realisation and effective performance; or, a vehicle for control over the intrusiveness and daily disruptiveness of pain, and therefore "a palliative, an analgesic, a way to fend off or escape pain, and a way to maintain self-efficacy and achieve self-realisation in spite of chronic pain" (Good, M., 1994: p. 50). Such suggestions do, however, reflect the scepticism often faced by those with chronic conditions. This will be discussed further in the next section.

Loeser and Melzack (1999) have noted that because chronic pain is "unrelenting, it is likely that stress, environmental and affective factors may be superimposed on the original damaged tissue and contribute to the intensity and persistence of the pain" (p. 1609). This indicates that usual approaches to pain do not always apply to chronic pain. Conditions like WCPP, then, may not respond in expected ways, which may result in the dismissal of the reality of the symptoms (when they are simply not fully understood). Certainly, these types of approaches are failing to alleviate the pain of these women.

### The mind and body in chronic pain

A condition like WCPP may struggle to align with any particular explanation of the nature of the body or its relationship to the mind and self, and again this lack of basis from which to make claims means that achieving a place on the policy or public agenda is difficult. It also means that internal wrangling about the proper

understanding of WCPP may detract attention from the pursuit of agenda visibility.

### *Body*

The problem of chronic pain is partly a question of the conception of the body. Like pain, the body may at first seem straightforward and well understood, but this is far from the case. Williams (2003) has described the chaos surrounding the concept of the body, as

“instead of the patient's body being at the centre of contemporary medical practice and discourse, we now find ‘multiple images and codings’, whereby the body is endlessly ‘doubled and redoubled’ through a self-referential chain of simulacra” (p.172).

Criticisms have been made of the basic biomedical model of the body, which is described as ‘mechanistic’. In this model, the body is conceived of as a system of organs, which may malfunction. This ideal body has clearly defined boundaries: “(w)here the body ends and the outside world begins is marked with precision, and is emphasised because this border is where the battle for health goes on” (Martin, 1999: p. 99), and the nature of the body is seen as “tightly contained, its boundaries stringently policed, its orifices shut, kept autonomous, private, and separate” (Lupton, 1999: p. 57).

The field of biopolitics has emerged in response to the attention being paid to the body and the incorporation of Foucauldian ideas about the regulation of the body (Gyorgy, 1996) and can in many ways be understood as the politicisation of the body (Heller, 1996). This concept of biopolitics as health has emerged as the concept of health has become less straightforward (Feher & Heller, 1994). The history of medicine itself has been described as a succession of ‘bodies’: the rational, anatomical, physiological, biochemical, psychosomatic, psychoneuroimmunological bodies and the body of experienced meaning (Levin & Solomon, 1990). The body is, therefore:

“an evolutionary biological entity, but not merely so. It is also an ongoing achievement of socialisation and acculturation, processes

which communicatively interact with its biological nature, and not only develop this nature, but permanently shape and transform it” (Levin & Solomon, 1990: p. 516).

In medical sociology, the body is understood at an even more abstract level:

“bodies and identities are simultaneously resources and constraints, objects of domination and agents of resistance. Bodies/selves are principal fields of political, economic and cultural activity, dominant tropes through which the tensions and crises of society are represented, usually in media of mass communication” (Brown, 2003: p. ix).

The body may appear as rather elusive in medical sociology, where it tends to be referred to as either belonging to another realm (e.g. – medicine, or biology), or socially constructed (Kelly & Field, 1996).

Feminism has also been criticised for being similarly somatophobic (Birke, 1999). Birke (1999) states that “any failure to engage adequately with biology (except to criticise it for determinism) fails those people (and non-humans) who are most readily defined by it, and who may suffer because of it” (Birke, 1999: p. 175). Instead, Birke argues, we need:

“an understanding of the biological body that links inner and outer, rather than presupposing a singularity to the body. We need, moreover, a biology that is not determinist, nor is seen as foundational or presocial. But nor do we need an understanding that simply dissolves boundaries in endless flows of information. Our biological bodies are not hermetically sealed; rather, they are in constant engagement with the ‘body’s world’... their very material structure itself – the flesh – to structure, even constrain, how that engagement takes place” (p. 174).

Because WCPP is chronic, painful and potentially tied to their reproductive biology, women may become more aware of their body than they were prior to the condition’s onset. Bullington (2009) has described how “(i)n health, I *am* my body, but when my body doesn’t work, I experience a split between myself and my body, and my body is no longer me” (p. 103). This means that conceptualisations of the body are central to the problem of WCPP, and that competing ideas about the body may obscure

understanding of the condition and themselves restrict the condition's ability to feature on a policy agenda.

### *Dualism*

Largely resulting from these problems in conceptualising the body is the problem of dualism. This is one of the major limitations to understanding of the body, theories of health and illness, and the fate of conditions like WCPP, as it is inherently reductionist (Tesh, 1988). The basic dichotomy noted above of subject/object (or me/not me) are accompanied by a number of other binaries that appear in theorising about the body, such as able or disabled, healthy or ill, normal or deviant, true or fictitious, social or physical, rational or emotional and mental or physical (Moss & Dyck, 2003).

One of the problems with the Cartesian mind-body split is that it seems to imply that the mind can control the experience of the body, as in the consciousness model outlined by Vrancken (1989) described earlier in this chapter. The underlying assumption here is that pain must be related to consciousness, because it is experienced by a conscious person (Devor, 2009). It is in this kind of thinking that the origins of the common lay response to 'toughen up' to pain or simply 'think positively' can be found; these rely on the equally common belief in 'mind over matter'. It is implied that a person that is self-reliant, capable and positive will not be a pain patient (Kugelmann, 1999). A variation on this idea is another that a person's character can be assessed by the way they respond to illness; a strong, resilient person will not be 'beaten' by disease, while a weak person will succumb to it (Pollock, 1993). Disease may be seen as "the will speaking through the body, a language for dramatising the mental" (Sontag, 1978: p. 44) and so to suffer from disease is "something quite preventable; an act of will, or rather a failure of will" (Sontag, 1978: p. 78).

Dualism may obscure that the body is "at one and the same time both biological and social, material and cultural, shaping and being shaped by ongoing social-cultural relations or liaisons, yet irreducible to any one domain or discourse" (Williams, 2002: p. 18). WCPP patients, then, may become victims of this sort of dichotomising.

There is the danger for women's symptoms to be psychologised, and the moral responsibility for illness be assigned to the woman herself, particularly when no organic pathology can be discovered.

### *Psychologisation*

Sufferers of chronic pain are often viewed sceptically because "what counts as objective in the contemporary order of things, (means that) pain that outlasts the mending of bones and tissue is subject to disbelief" (Kugelman, 1999: p. 1669). When, as sometimes occurs with WCPP, physical explanation cannot be found, psychological explanations are often turned to (Steihaug, Ahlsen & Malterud, 2002; Reid et al., 2001), resulting in victim-blaming (Ballweg, 1997). This can be distressing for patients, who may feel that their moral character is being questioned (Werner & Malterud, 2003). This is concerning, because it may label patients with psychiatric disorders when they are still in the early stages of a chronic condition and still 'coming to terms' with it (Howell, 1994), and because this link between psychological factors and illness implies a link between *personality* and illness. This has the potential to "redefine the source of illness as the self rather than biology or chance or socio-economic circumstances" (Pollock, 1993: p. 68), and may therefore result in the removal of support (in terms of medical resources, treatment, financial assistance, etc.) for the patient. It is also concerning that this psychologisation of symptoms may "lead to diagnostic errors, to inappropriate treatment, and to a great deal of unnecessary suffering" (Goudsmit, 1994: p.11). It may be that "recurring unpleasant symptoms, like pain and nausea, can undermine a (patient's) self-confidence and self-esteem" and that this could mean that "emotional problems may often be the *result*, rather than the cause of certain conditions" (Goudsmit, 1994: p.8, italics added).

This is not to suggest that psychological factors should not be considered in chronic conditions. It is certainly important for biological variables to be considered alongside psychosocial and cultural ones (Fillingim, 2009; Birke, 1999). It is simply to warn along with Kerns and Jacob, 1992, that it is

"unfortunate...that research and clinical wisdom generally continue to view the relationship between the experience of pain and psychosocial

variables in unidirectional terms; that is, that chronic pain may be *either* caused by psychosocial factors or provokes psychosocial sequelae” (Kerns & Jacob, 1992: p. 236).

### *Visibility*

Perhaps the most pronounced dichotomy, particularly in the biomedical model, is that between visible and invisible pain (Kugelman, 1999). Biomedicine places great importance on vision, which, as Gordon (1988) has explained:

“fosters the sense of separation between subject and object, particularly when compared to touch, and supports a physicalist interpretation of the elements of reality as things-in-themselves. It enhances a sense that the knower is autonomous, free to choose from everything he/she sees. Finally, vision allows for the quickest route to the mind and abstraction” (p. 33).

Although some are prepared to acknowledge that all pain is subjective, and in this way ‘invisible’, therefore requiring communication (Jackson, 1994b), medical technologies have given us the ability to ‘see’ inside the body in unprecedented ways. The dependence on vision means that a patient’s account may be discredited if visible ‘evidence’ cannot be produced to support it (Whelan, 2009; Rhodes et al., 1999). This means that those conditions that cannot be ‘seen’ may be marginalised, as has occurred with WCPP. (This may also help to explain why any attention to the issue has crystallised around endometriosis, as this is a condition that can be ‘seen’ through laparoscopy. This will be discussed further in Chapter 4).

Women with chronic pelvic pain may be subjected to a number of tests, some of which involve imaging (e.g. – ultrasound) and the attempt to ‘see’ the problem. These may force women to consider their body in new ways, and imply that women are not capable of knowing that there is something ‘wrong’ with their body themselves. Rhodes et al. (1999) describe the (mis)match between body and image:

“The images seen by pain patients, while negative in their connotations...call on the patient to align herself with their reality, demanding to be read as factual evidence of a match between the



inside of the body as 'specimen' and the inside of the body as the private and incontrovertible ground of experience" (p. 1193).

Imaging technologies and other medical technologies designed to 'see' into the body are "powerful across social and cultural boundaries: they serve as insurance arguments, self-help diagnoses, legal claims for reparations, and popular arguments against the stigma of mental illnesses" (Dumit, 2000: p. 223). In these ways, the medical gaze brings disease "into being as objects of consciousness and intervention" (Greenhalgh, 2001: p. 4).

Critics of the biomedical model suggest that this ability to 'see' is often mistaken for the ability to 'know' (Greenhalgh, 2001). Rhodes (1999) proposes that biomedicine may be able to overcome this limitation by finding new ways to interpret these images:

"Perhaps the visual orientation of medicine could be enlisted to produce individualized representations of the body that legitimise pain without the expense and ambiguity of current forms of testing. Another possibility would be to actively engage patients' desire for agency and self authorship in the exploration of alternative solutions" (p.1201).

Biomedicine is not the only culprit here. Society in general also often grants greater legitimacy and credibility to those who are visibly suffering or impaired, although it may also lead to stereotyping and discrimination (Thorne, 1993). Mitteness (1995), discussing urinary incontinence, has suggested a kind of continuum of legitimacy, from successfully managed and totally invisible to unmanaged and highly visible. Those with 'invisible' conditions, like women with chronic pelvic pain, thus encounter a different kind of stigma (Charmaz, 1999; Ware, 1992), which may interfere with care-seeking, treatment and long-term outcomes (Slade, Molloy & Keating, 2009). Intensifying this is that they have few ways to counter this, as often their condition cannot be adequately explained, leaving women to "grapple with the anguish of an apparent meaninglessness of pain" (Grace, 2003: p. 58).

## Narrative

This problem is exacerbated by the common contention that pain cannot be put into words, and that chronic pain, in particular, is “deeply resistant to language” (Good, B., 1994: p. 47). The work of Scarry (1985) established the theory that

“(w)hatever pain achieves, it achieves in part through its unshareability, and it ensures this unshareability through its resistance to language...(But pain) does not simply resist language, but actively destroys it, bringing about an immediate reversion to a state anterior to language...” (p. 5).

Thus it has been claimed that

“(w)ords simply cannot describe the brutal realities of unending pain and fatigue. Such pain forces the mind to attend to the body, robbing people of their faculties for rational judgment and blinding them to the structural source of their distress” (Greenhalgh, 2001: p. 17).

Similarly, Jackson (2005) has suggested that pain may seem

“resistant to language, impossible to represent, a succession of meaningless moments that defies translation and achieves no transcendence...an experience about which there is increasingly nothing to say, nothing to hope, nothing to do” (p. 231).

However, the problem may not necessarily be that pain is inexpressible, but rather, that it competes with everyday language. Jackson (1994b) describes how patients may feel that “language is inadequate, or the handmaiden of the professionals” (p. 219) or “distorted, bizarre, pointless or trivial” (p. 220). She also describes how patients may feel as if they have to depend on this ‘everyday’ language, for although

“they report feeling profoundly misunderstood, pigeonholed, and categorised by everyday-world language, this is the language they continue to pin their hopes on...The problem is that this meaning is unacceptable: this meaning is an abomination, it is hell itself; no one should be in constant, severe pain...(and so they) long for an adequate everyday-world explanation” (Jackson, 1994b: p.222).

Language and narrative do have a crucial role to play in health, illness and medicine. Part of the difficulty, as Jackson suggests, is that this language is normally that of biomedicine, which “insists on reducing our bodies to constituent parts; how we live our bodies is intimately affected by the power of that language” (Birke, 1999: p. 159). This language is insufficient for describing the experience of pain. While the dominance of the biomedical approach had seen the diminishment of the patient narrative, the rise of chronic illness has challenged the biomedical model and placed narrative analysis back in the spotlight (Bury, 2001). Certainly narrative provides a means by which to “restore the meanings that have been lost by recovering the voices that have been silenced: the voices of the ill themselves” (Greenhalgh, 2001: p. 323) and “a way to resist the medical construction of one’s identity” (Greenhalgh, 2001: p. 324).

Frank (1995) has also identified three basic narratives of illness, the restitution narrative, which anticipates getting well, and gives prominence to the technology of cure; the chaos narrative, in which illness seems indefinite, without respite; and, the quest narrative, about finding that illness can be transformative (Frank, 1995). Creating a narrative of this sort may help the patient to deal with the problem of meaning (Hyden, 2005; 1997). They may also shift the focus of illness from passivity to activity, so that ‘lack’ becomes ‘production’ (Williams, 1998). Narratives are essentially stories, for as Carr, Loeser and Morris (2005) explain, they are

“not solely or necessarily verbal but embraces visual, bodily, kinetic, musical and mixed media forms of storytelling. It incorporates in its inescapable gaps and silences what will not, cannot, or must not, be said. It is always constructed...As an adjective, *narrative* refers to elements associated with stories or storytelling: character, plot, episode, image, theme, temporality, language, point-of-view...” (p. 6).

Narrative, then, is a highly accessible tool. The suggestion of alternatives is closely linked to the agenda-setting process (Kingdon, 1995 [1984]), and that of narrative medicine may be a useful one in terms of WCPP, not only from a clinical perspective, but also from a policy one. In the same way that health promotion activities are prescribed, so might attempts for this kind of endeavour be. Hyden (1997) has suggested potential uses of the illness narrative as the transformation of illness events

and construction of a world of illness; the reconstruction of life history in the event of chronic illness; the explanation and understanding of illness; a form of strategic interaction to assert or project identity; and, the transformation of illness from an individual to a collective phenomenon. Narrative, as the 'voice of the lifeworld' can release the individual from their role as patient, and recontextualise their illness experience (Bury, 2001; Young, 1997).

Grace (2008) suggests that, in the case of WCPP, women's narratives highlight "the strangeness or incredulity inspired by a discourse of the pelvic organs and viscera that disassociates them from any subjectivity...(instead their narratives are) about a complex set of experiences, a nexus of experience...for which there is *no-place*; an absence of location within a discourse entirely anchored in a primacy of location within the body" (pp. 184-185).

Narrative, then, may serve to release women from the confines of their bodies and the biomedical model that they are often constrained by (Grace & MacBride-Stewart, 2007a).

Although the language of biomedicine may be considered inadequate, the potential for medicine to develop narrative is tremendous. Indeed, medicine itself has been described as "fundamentally narrative" (Hunter, 1991: p. 5). Hunter (1991) analogises physicians to literary critics, capable of (or perceived to be capable of) 'reading' the body. She describes how the physician

"not only grasps (and often ferrets out) the patient's story, but one who is also knowledgeable about the habits and expectations of patient-narrators and understands that the way the story is told is part of its meaning" (p. 8).

Hunter explains that from this patient narrative is formed a medical 'metastory'. Medicine "has the power not only to *rewrite* the patient's story of illness but also to *replot* its course" (p. 139. *italics added*). Narrative is therefore presented as useful to both patient (for whom it keeps the physician in their 'proper' (subordinate) place) and physician (for whom it serves as a way of confronting illness and "enables clinicians to describe the non-linear, subjective, and uncertain aspects of their experimental field" (p. 166). Morris (2005) defines narrative medicine as:

“medicine practiced with attention to the skills and competencies required to understand how patients and caregivers and health care providers live in an environment of stories” (p.271).

However, narrative medicine may be extremely difficult to practice, particularly within the biomedical paradigm. As Nettleton, O'Malley and Duffey (2004) have explained in their analysis of patients' narratives of medically-unexplained symptoms (MUS), the stories are difficult to tell and hear, and there is no clear path to technically competent help: “there are no drugs or treatments to try (and) no medical breakthroughs to hope for” (p. 61). As they note, employing narrative can be particularly difficult with MUS (as WCPP may often be) when there is not even biomedical vocabulary to draw upon.

Narrative medicine is, nonetheless, one way to understand illness as part of the human condition (Charon, 2005; Loeser, 2005a) and may apply particularly well to chronic conditions, as it provides a unique vantage point for understanding the implications of chronicity. Townsend, Wyke and Hunt (2006) have emphasised that the control of symptoms may not be the most important aim of treatment to a patient confronted with the loss of identity and important relationships as is often assumed in the biomedical approach, and narrative may be a useful way to better understand these and other more intangible elements of such conditions as WCPP. Grace and MacBride-Stewart (2007a) have argued for ‘women’s words’ to be better utilised in the treatment of WCPP, particularly in terms of incorporation into pain measurement techniques, particularly questionnaires, and a greater focus on interviews.

If a problem cannot be adequately described, its chances of gaining a place on a policy agenda remain slim. The definition of a problem is essential for defining action that can be taken (Dery, 1984), and influence the probability of a favourable policy outcome (Rocheffort & Cobb, 1994). In the case of chronic pain, and conditions like WCPP, there are several barriers to narration, such as invisibility; that so much is at stake, it becomes a ‘loaded topic’, constantly contested; the challenge of the mind/body dichotomy; the subjective nature of the experience; and, not least, the influence of those disciplines most authorised to influence meanings (biomedicine and

psychotherapy) (Jackson, 2005). This is a problem, then, at both a policy level and the individual patient level.

The inclusion of patient narratives and narrative medicine would challenge existing doctor-patient relationships. These relationships are crucial in a consideration of WCPP, from both a patient and a policy perspective, as the doctor-patient relationship and the clinical encounter have attracted a lot of attention in the latter half of the twentieth century.

### Doctor-patient relationships

The doctor-patient relationship is the site at which the micropolitics of health and illness are played out. The nature of this relationship is indicative of the power of the biomedical model of health and illness. Both medical professional and patient may be potential advocates for a condition like WCPP (Milstead, 1997), and it is important to consider the clinical encounter as a crucial stage in awareness raising and issue definition.

May et al. (2004) describes how these investigations into the clinical encounter have been motivated by hopes that understanding it would lead to better patient compliance with treatment regimens, undergird by the belief that the doctor-patient relationship itself could affect outcomes. Traditionally, the model of the doctor-patient relationship is a paternalistic one, in which the doctor has been understood to have

“exclusive control over the definition and dispensation of relevant medical knowledge regarding diagnosis and therapy and the patient accepts both the authority of the doctor to exercise this control and the consequent legitimacy of his decisions. Doctors are active and patients are passive” (Salter, 2004: p. 31).

It has also been commonly assumed that both doctor and patient are rational agents, capable of “actively calculating, assessing and countering expert medical knowledge” (Salter, 2004: p. 45). The legitimacy of the doctor derives from their clinical and scientific expertise and monopoly of access to patients, the prescription of drugs and ability to perform surgery (Cooper, 2001; Coburn & Willis, 1999), and is possible because of the assumed emotional dependence of patients on doctors (Salter, 2004).

In these kinds of models, the patient is also often assumed to be hostile, and this hostility is thought to adversely affect the outcome of the consultation (Selfe, Matthews & Stones, 1998).

This understanding of the clinical encounter links to concerns about biomedicine. It is charged that

“doctors listen for *symptoms* – medical evidence of what the patient could be sick with or signposts of the progress of an already diagnosed disorder...(and their) power and authority in the medical encounter derive from their gatekeeping position in the social structure of Western medicine” (Lorber, 1997: pp. 40-41).

As noted in the previous chapter, physicians are also inclined (due to their training in the biomedical worldview) to use biomedical discourses of objectification, quantification, pathologisation and amelioration (Greenhalgh, 2001). Concerns may also be raised at the seeming dilemma for medical practitioners in the potential contradiction of service provision versus profit (Loustaunau & Sobo, 1997).

May et al. (2004) have maintained that these perceived flaws in the biomedical approach are in fact not so prevalent in the clinical encounter as is commonly assumed, at least at the level of primary care, where they declare biomedical reductionism of this kind to be “ultimately impossible” (p. 151). Instead, these authors describe physicians as troubled particularly by the subjective nature of patient’s experience. The authors suggest that chronic illnesses are

“frequently troubling because it is not clear what, if anything, can be done about them – and because clinical uncertainty about aetiology and remedy threatens the authority upon which doctors rely to frame and enact medical knowledge and practice, and thus its outcomes” (p. 145).

Other authors have also noted the beginnings of an ideological shift from hegemony to uncertainty in the understanding of medicine (Salter, 2004). These uncertainties include:

“forms of uncertainty that stem from the impossibility of mastering the entire corpus of medicine’s knowledge and skills; from the many gaps

and limitations in medical knowledge and effectiveness that exist despite medicine's continued advances; from difficulties associated with distinguishing between personal ignorance and ineptitude; and the lacunae and incapacities of medicine itself...(and) the uncertainties and mysteries of human illness, and its attendant pain and suffering" (Fox, 2002: p. 237).

This uncertainty is also related to a general erosion of trust in social institutions witnessed in the last part of the twentieth century (Mechanic, 2001). May et al. (2004) suggest that along with this ideological shift, the rise of health consumerism has seen the analysis move from doctor-centred models of the consultation as an encounter about negotiation of expertise: that of the professional knowledge of the doctor, and the experiential knowledge of the patient.

The clinical encounter may also be understood in terms of an alliance. Peters et al. (1998) have suggested that, particularly in chronic illness, the doctor may be seen as an ally in overcoming the condition. Chronic conditions often give rise to a different type of consultation, as the often intractable nature of the condition forces the patient (and doctor) to acknowledge the limits of medical science (Thorne, 1993).

The rise of health consumerism and the amount of information now available to patients has also meant that patients may approach their doctors 'armed' with information and even a self-diagnosis (Bury, 2001; Cooper, 2001). The internet, especially, has democratised access to information (Klawiter, 2008a). This may be burdensome, as well as empowering; women's access to information means that there is "no natural end – no temporal limit – to the confusion and the uncertainty" (Klawiter, 2008a: p. 272). The emergence of concepts such as patients' rights, patient participation, patient empowerment, and patient satisfaction, has led to more examination of the patients' side of the clinical encounter.

Peters et al. (1998) described patients' requirements of doctors as threefold: having the problem named, having an explanation that involved them as the patient, and engagement with the problem. This last requirement indicates that, for some patients, the process of the clinical encounter may in fact be valuable in similar ways to the outcome of it (Peters et al., 1998). Cooper (2001) has echoed these requirements when



listing the expectations and needs of patients from doctors, adding only the relief of symptoms, usually the most immediate need of a patient from the clinical encounter. Bransen (1992), in her analysis of the medicalisation of menstruation, has identified the different ways in which women perceive their doctors when consulting for menstrual complaints. In what she describes as the emancipation genre, the patient 'makes use of' a doctor as a critical and well informed consumer; in the objective genre, the patient goes to be treated, and expects the doctor to be an expert; and, in the natural genre, the patient sees the doctor as superfluous.

Steinmetz and Tabenkin (2001) have investigated family doctors' attitudes to 'difficult patients', who may be those with behavioural problems, repetitive, unsolved or multiple complaints, and those with psychiatric disorders. Women with chronic pelvic pain may be 'difficult' patients in this sense, as their condition is ongoing, often unsolved, and may involve many different symptoms and complaints. These authors found that doctors coped with such patients through empathy, listening, establishing a framework for the encounter, directness, humour, confrontation and cooperation with the patient. Doctors also reported developing techniques to help them deal with the way they responded to these patients, such as relaxation and resignation to the situation (Steinmetz & Tabenkin, 2001).

Grace's (1995) of women's experiences of using the health services for chronic pelvic pain in New Zealand reported that patients often felt disempowered by the medical consultation, as

"symptoms are extracted via an examination by technology, not through her own speech or interpretation of her experience of pain.

The symptoms are those revealed through the medical examination"

(p. 10).

She notes that some women do not even receive examination, but, rather, are ignored, dismissed and silenced, suggesting that symptoms may have been normalised or even psychologised.

Examination of the patient's role in the clinical encounter has led to calls for patient-centred care, based on the assumption that patients want to participate in decision making about their own bodies. Coulter and Fitzpatrick (1999) state that this is hoped

to lead to more individualised forms of care, as well as the provision of care in new ways, but warn of the dangers, namely, that it could place additional stress on the patient, cripple the health system, and increase inequality in health services.

The clinical encounter is further complicated by the issue of gender. There has been a great deal of attention given to medicine by feminist scholars, and the issue of gender has become an important one partly as a result of this. This is particularly true of a condition like WCPP, which is potentially linked to a women's reproductive biology and thus imbued with greater significance.

### Gender

The historical experience of women in medicine and society is the foundation of the problem of gender still debated in health and medicine. Werner & Malterud (2003) have described how

“medical theory and practice has historically been developed by men and still reflects the hegemony of health disorders; mostly striking men. The women patients' chronic pain and ill-health behaviour break with normative, biomedical expectations of what illness is and how it should be performed” (p. 1417).

A quick mention needs to be made of the distinction drawn between the terms 'sex' and 'gender'. 'Sex' is usually used to denote a biological state, whereas 'gender' is usually used to denote the social reality of sex (Doyal, 1998). However, Grace (2006, 2004) has outlined the problems feminist scholarship has explored with such a description, and suggests that this conception of 'sex' as 'natural' is a simply a reflection and reinforcement of pre-existing concepts of gender and gender relations (Grace, 2004).

Gender has also been described as an ideological structure, as “based upon sexual difference, the gender structure imposes a social dichotomy of labour and human traits for women and men, the substance of which varies according to time and place” (Lazar, 2005: p.7). Furthermore, gender ideology is hegemonic:

“it often does not appear as domination at all; instead it seems largely consensual and acceptable to most in a community...largely accomplished through discursive means, especially in ideological assumptions are constantly re-enacted and circulated through discourse as commonsensical and natural” (Lazar, 2005: p.7).

The problem in terms of medical practice and its application to conditions like WCPP is that “gender-based roles and expectations can and do influence scientific inquiry and the interpretation of data” and may even “preclude certain questions from being asked, or may cause discordant but accurate information to be disregarded” (Bertin & Beck, 1996: p. 40).

The problem of WCPP is thus a complicated one, as it must be understood as occurring within a certain sociocultural context, which includes (mis)conceptions about gender. Women’s bodies are often conceived of as “‘open’, as ‘leaky’, as possessing too many orifices” (deRas & Grace, 1997: p.10), and this is obviously particularly likely in the case of WCPP, so often linked to menstruation. This idea of women’s bodies as fluid, or flexible, is worth considering. Birke (1999) suggests that “it seems to lose sight of the ability of the biological body to be self-organising and self-determining – to be transforming within itself” (p. 169), while Martin (1999) suggests that while it may masquerade as liberating, it is actually a regulatory discourse, as flexible bodies “cannot stop moving, they cannot grow stiff and rigid, or they will fall off the ‘tightrope’ of life and die” (p. 112). Flexibility and fluidity are only “a tiny portion of human capacities” (Martin, 1999: p. 113), and these authors argue women should not be constrained within this model.

It is worth noting too that women are more likely than men to be thought to have psychogenic origins for their pain (Goudsmit, 1994; Bendelow, 1993). This is clearly linked to ideas of women as “weak, suggestible, emotionally unbalanced, irrational, manipulative, and unable to cope with even relatively minor stress” (Goudsmit, 1994: p. 8), and the implication is that women exaggerate or imagine their symptoms. This may be one reason why men are thought to be more likely to receive medical attention and be taken more seriously when it comes to their illness complaints (Bendelow, 1993). Grace (2001a), has described a ‘silence’ around psychological factors and

symptoms in women, which is “filled with disconcerting inferences and superstitions about ‘women’ and ‘hysteria’ and ‘being neurotic’” (p. 422).

It has been charged that, in medicine, the female body is traditionally perceived as the ‘other’ (deRas & Grace, 1997), while the ‘normal’ body has been that of a middle-class, young-adult, white man (Lorber, 1997), creating a ‘woman-as-other, male-as-norm lens’ in medicine and health (Hoffman & Massion, 2000), with the effect of denying or pathologising difference (Birke, 1999). Historically, female patients have been considered “by nature sickly...at the mercy of her ovaries and uterus” (Krieger & Fee, 1996: p. 17), “silly, self-indulgent and superstitious” (Ehrenreich & English, 1973: p. 79). Similarly, the female body has been seen to represent both the ‘perfect’, symbolising “nature, beauty, unity, health, moral virtue and regularity” but also the ‘imperfect’, “the ‘uncivilised’ body: inhibiting as well as creating disease, weakness, uncontrollability, irregularity and abnormality; the unhygienic body” (deRas & Grace, 1997: p. 10). It is often suggested in feminist literature that gender stereotypes of this kind “permeate all levels of the health care system, and can be found in the interactions between doctors and patients, as well as in textbooks and laboratories” (Loustaunau & Sobo, 1997: p. 41).

The medical system, then, is perceived as “a powerful instrument of social control, replacing organised religion as a prime source of sexist ideology and an enforcer of sex roles” (Ehrenreich & English, 1973: p. 83). Concern that “women’s invisibility has hindered and continues to impair equal quality of health care” (Hoffman & Massion, 2000: p. 4) has led to an increased focus on the role of gender in health, based on the idea that “being male or being female is a core aspect of our bodies as well as our identities, that thoroughly influences all domains of life including health” (Bekker, 2000: p. 18). Women are considered to have healthcare requirements both because of their biology (reproductive health concerns) and their social roles (e.g. caring for families) (Thomas, 1998).

In examining the role of gender in health, then, differences are inevitably sought (Robinson, Riley & Myers, 2000; Hubbard, 1990). It has been suggested, for example, that males and females respond in different ways to analgesia (Fillingim, 2009). It has also been found that women are higher users of health services than males, often

accounted for by the need to consult for reproductive processes (Bekker, 2000). This, essentially biological, explanation has been criticised on the basis that they may lead to “a mistaken naturalisation of gender divisions that are essentially social in origin” (Doyal, 1995: p. 16). Differences in health can be accounted for in other ways, such as that women

“will be exposed to different health risks, both physical and psychological. They have access to different amounts and types of resources for maintaining or promoting their own health and may also have different levels of responsibility for the care of others. If they become ill they may have very different strategies for coping. They may define their symptoms in very different ways, will probably seek help from different sources and may respond very differently to treatment” (Doyal, 1998: p. 9).

Women are also thought to have different relationships with their bodies, such as heightened ‘body awareness’, again due to their reproductive potential (Bekker, 2000), and to be better equipped to deal with their bodies. Bendelow (1993) has observed the ‘myth’ that women have a natural capacity to endure pain, and, therefore, that they are *expected* to cope with pain. She suggests cultural reasons for this assumption, including a greater readiness to report pain/talk about feelings; greater likelihood that they will act on symptoms/seek support or help; childhood socialisation to develop and encourage caring for others/imagination about how it feels to be in pain/distress; and, that women’s ontological security and sense of identity may be less threatened than men’s by admission of being in pain (Bendelow, 1993).

The attention being paid to gender differences in health is by no means uncontested. It has also been suggested that differences “become scientifically interesting only when they parallel differences in power...Sex differences are interesting in sexist societies that value one group more highly than the other” (Hubbard, 1990: p. 129). As Krieger and Fee (1996) have pointed out “we know about race and sex divisions because this is what our society considers important. This is how we classify people and collect data” (p. 15). Doing so, it is suggested, will obscure environmental and social determinants of health. Similarly, Grace (2006) argues that “while gender-specific medicine as a field continues to argue for and embrace the sex/gender distinction, it

will endorse the attendant dichotomising and thus essentialising of biological sex” (p. 151). Such arguments rest on the case that women are at least as different as they are alike. It is suggested that “to know a person’s sex is to know very little”, as women are not, as is sometimes assumed or implied, “a single group defined chiefly by biological sex, members of an abstract, universal (and implicitly white) category”, but are, in reality, “a mixed lot, our gender roles and options shaped by history, culture, and deep divisions across class and colour lines” (Krieger & Fee, 1996: p. 23). Furthermore, there is the danger that “differences are being observed in *individuals*, not in the biological or the psychosocial ‘basis’ for the differences” (Grace, 2004: p. 135, italics added) or that population-level differences are considered to apply to individuals (e.g. – because women are known to be higher users of health services, assuming that any given individual woman will be more likely to visit a doctor in the case of illness than any given individual man) (Berkley, 2000).

### *Women’s health*

There is consensus, however, that women’s health needs to move beyond obstetrics and gynaecology, and the focus has come to rest more upon service provision (Ussher, 2000). Krieger and Fee (1996) have outlined three steps to creating an alternative perspective, beginning with the recognition that categories we treat as biological are actually social and the realisation that we need social concepts to understand these. The development of social measures, and strategies for a new kind of health research, can then proceed from this.

It has been suggested that an interdisciplinary women’s health movement would instead focus on issues like the systemic effects of ovarian hormones, the chronobiology of the menstrual cycle, sex role expectancies, cognitive/affective factors, social learning, genetic factors, blood pressure, and differences in endogenous pain inhibition (Fillingim, 2000; Hoffman & Massion, 2000). These authors are still focussed upon sex differences and the conditions that mark women out from men, and such models do not seem to have considered what good such knowledge will do. While it is regularly bemoaned that there is not sufficient medical knowledge of menstrual processes (Scambler & Scambler, 1993), it is possible that fuller knowledge of the ‘normal’ menstrual cycle may simply serve to further pathologise and

medicalise those women who do not conform to this norm. The situation of women with either natural or medically-induced amenorrhoea (absence of periods), which is already often described in terms that make these women appear 'less than' female (Lupton, 2003), may be even more emphatic.

The American College of Women's Health Physicians (ACWHP) has outlined the principles for a more holistic women's health, with a 'woman-as-norm' foundation, that focuses on women-centred care, the respectful use of power, diversity, activism, eclectic healing practices, complexity, and, individual and organisational wellbeing (ACWHP, 2005). One difficulty in taking this broader approach is that 'laundry lists' of issues may appear (Olesen & Clarke, 1999). Priority setting needs to be considered by advocates for women's health in order to ensure positive outcomes.

Rogers (2004) has suggested ways to begin to redress the gender imbalance in research, such as withholding funding, withholding ethical approval, refusal to publish, revising evidence hierarchy, improving career pathways, and better employment conditions. The investigation of gender differences may prove useful to WCPP, but the dangers of such an approach have also been clearly outlined. Certainly gender prejudices and imbalances must be avoided where possible. From a policy perspective, it seems certain that there are other avenues of inquiry better pursued than that of simply sex differences.

### Medicalisation of 'women's troubles'

One area of these gender concerns that does require further examination is the medicalisation of so-called 'women's troubles'. As was discussed in Chapter 2, 'normal' life processes are often now seen as medicalised, as the body is the domain of medicine in Western culture. This is particularly so in terms of *female* life processes (and life processes that are more significant for women for social reasons, such as ageing.)

Perhaps the most obvious example of the medicalisation of women's health issues is the medicalisation of menstruation, a topic clearly linked to WCPP. Riessman (2003 [1998]) has described how the menstrual cycle has been "transformed from a

misunderstood and somewhat contaminating female phenomenon to a hormonal process of puberty and preparation of the uterus for pregnancy” (p. 55). She has warned that “the encouragement of girls and women to seek medical help for any and all menstrual problems contaminates the status of womanhood with the expectation of regularly recurring illness” (p. 55).

Menstrual problems of various kinds are certainly common; Anastasakis et al.’s 2008 study of university students found that one in three had received some treatment for their menstrual periods. Similarly, Deb (2008) found that 40-70% of women experience dysmenorrhoea, and that pain is significant (limiting of activities) in 5-20% of women. Ballard, Lowton and Wright (2006b) suggest that menstrual problems are largely a problem or bad luck, rather than illness. Such an explanation not only gives great credence to poorly understood biological, physiological and hormonal factors, but also gives little relief to patients.

Bancroft (1995) has noted three major ‘problems’ associated with the menstrual cycle: pain, heavy bleeding, and premenstrual syndrome, which last would perhaps be better understood in terms of emotional and cognitive disruption/alteration. While it is commonly assumed that women’s cognitive performance is lowered in the premenstrual phase, this does not in fact appear to be the case (Richardson, 2000). It seems that while the menstrual cycle is important in terms of the *content* of cognition, it has little or no impact upon cognitive processing (Dye & Richardson, 2000).

The medicalisation of menstruation is at least partly due to the menstrual experience of many women. It is often contended that “(w)omen experience pain as part of normal reproductive life in a manner that has no analogy in men” (Stones, 2000: p. 355).

Hubbard (1990) has noted the lack of research into the menstrual cycle, despite the increasing tendency for it to fall under the ‘treatment’ of biomedicine. Similarly, femininity may be seen as pathological in itself; women may be seen as being controlled by their hormones and reproductive biology (Nicolson, 1995; Laws, 1990). In this way, the medicalisation of ‘women’s troubles’ may lead to the marginalisation of women; a concern particularly relevant to WCPP.



Lee (2003) claims that women are socialised (by a patriarchal, biomedical society) to experience menstruation as something happening *to* them, thus fragmenting the self. She states that the negative attitudes of society to menstruation are likely to influence the ways women view their own menstruation. Menstrual etiquette is often imparted from an early age, and women commonly attempt to conceal menstruation, meaning the topic remains taboo (O'Flynn, 2006). Martin (1987) describes how menstruation may also be interpreted in a sinister way, as a negative process, that of *not* reproducing. She explains that given the mechanistic nature of the biomedical model of the body, menstruation

“not only carries with it the connotation of a productive system that has failed to produce, it also carries the idea of production gone awry, making products of no use, not to specification, unsalable, wasted, scrap...” (p. 46).

Scambler and Scambler's 1985 investigation into consulting behaviour has identified four basic menstrual attitudes: acceptance, demonstrated by 25% of women surveyed, in which women saw their periods as 'normal'; fatalism (27%), in which women felt their period were a 'nuisance', but were resigned to menstruation; and antipathy (48%), in which women felt a dislike of menstruation, and tended to view it as 'unclean', 'unhealthy', etc. This indicates that many women may feel negatively about their menstrual cycle.

However, menstruation need not necessarily be understood in these terms. One biologist has even suggested that menstruation can be understood in terms of a defense mechanism against pathogens, particularly sperm (Profet, 1993). It may also be linked to positive notions of femininity, such as the achievement of sexual maturity, fecundity, lack of pregnancy, normality, bodily order, good health and bodily renewal (Lupton, 2003). Despite these possibilities, menstruation, like other aspects of women's health (particularly menopause) is still surrounded by taboos, which serve to “mark out the woman as the Other, as different, whether she is represented as contaminating or as vulnerable and in need of protection” (Lupton, 2003: p. 152).

Another indication of the medicalisation of the female body is the rate of hysterectomy. One in five Australian women are expected to have had a hysterectomy by the time they are 50 (Graham, James & Keleher, 2008). Dell (2000) suggests that one reason for the high rate of hysterectomy is that women have become less willing to live with gynaecological symptoms. In fact, this is simply one part of the puzzle. Coulter (1988) identifies three critical decisions that lead to hysterectomy: the patient's decision to consult, the general practitioner's decision to refer to secondary care, and the consultant's decision to operate.

As was noted in the more general discussion in the previous chapter, the role of laypeople (patients) in medicalisation should be remembered, and instances of demedicalisation must also be accounted for. However, Oianas' 1998 study of medical advisory columns suggests that, while young women may seek 'medicalising' accounts of their menstrual experience, doctors are often all too willing to indulge this and encourage young women to understand their bodies and menstruation in biomedical terms. Although Oianas emphasises the role the young women themselves play in the medicalisation process, she notes that "they also express an inability to know and understand the body without a doctor's assistance" (p 58). She describes how doctors "use the columns as a means of socialising young women to become regular and obedient users of medical services" (p. 59). Oianas suggests that these young women are encouraged to see their bodies as autonomous, somehow strange and separate from them, that may fail, and cross the boundaries of normality. Because they cannot understand their body, they must put themselves in the hands of medical professionals; she identifies a strong discourse of medical sovereignty in knowing and understanding the body.

### *Menorrhagia*

Menorrhagia (heavy or prolonged periods) is worth considering here in the context of menstrual problems. Menorrhagia is clinically defined as a blood loss of over 80ml during a period, and has been estimated to occur among 20-30% of menstruating women (Santer, Warner & Wyke, 2005). It is commonly treated by medically-inducing amenorrhoea, normally by the use of a levonorgestrel-releasing intrauterine

system (LNG-IUS), such as the Mirena (Hill, 2009), which will be discussed next chapter with relation to the treatment of endometriosis.

Because menstrual loss is self-reported, it is subjective, making diagnosis difficult (Protheroe & Chew-Graham, 2005). It is often signalled by clotting, flooding, excessive sanitary product usage and social/professional disruption (Bulmer, 2008). It has been suggested that women are guided by their own menstrual experience; they tend to consult when their loss becomes *heavier* (O'Flynn & Brittan, 2000). The likelihood of reporting heavy or prolonged bleeding was also affected by the attitude women took to their periods (e.g. – if they viewed their body in mechanistic terms, then heavy or prolonged loss was often interpreted as malfunction) (O'Flynn & Brittan, 2000). Warner et al. (2007) have noted that in a quarter of cases they examined, doctors mentioned heavy or prolonged bleeding as a reason for referral to secondary care when the patient did not consider it an issue. Menorrhagia was also diagnosed in 30% of women whose doctors had not given it as a reason in referral (Warner et al., 2001). This suggests a predilection towards the diagnosis of menorrhagia (Santer, Warner & Wyke, 2005), despite the difficulties already noted, the frequent lack of organic pathology found in investigations, and the current trend of the rejection of hysterectomy (once a common 'treatment') as a recourse (Hill, 2009; Brandsborg et al., 2008; Merrill, 2008; Teo, 1990). Protheroe and Chew-Graham (2005) note that this trend away from surgical intervention may be problematic, as women tend to only see something that is *done* to them as treatment. Interestingly, they also note that women may wish to avoid hormonal treatment when a diagnosis has not been reached.

Menorrhagia is thought to account for around 20% of gynaecological consultations (Nicholson et al., 2003), which indicates women's desire to seek external validation for their symptoms, and for symptom relief (O'Flynn & Brittan, 2000). This indicates that the biomedical approach remains the dominant one with regard to menstruation and particularly menstrual problems.

## **Conclusion**

Women with chronic pelvic pain are faced with a myriad of issues, partly due to the politicisation of the body. It has been shown in this chapter that WCPP does not easily fit into the dominant approaches taken to understand the body, pain, health and illness. Because of this, not only may patients feel cast adrift from the health system, but their condition may fail to attract policy and public attention. The following chapter will investigate how breast cancer has attracted this kind of attention, and how endometriosis, one cause of WCPP, might learn from this example.

## CHAPTER FOUR

### COMPARATIVE ANALYSIS: ENDOMETRIOSIS AND BREAST CANCER

#### Introduction

This chapter consists of a comparative analysis of two important issues in women's health, affecting large numbers of New Zealand women: endometriosis and breast cancer. There are sufficient similarities between these two conditions to allow effective comparison. Despite these similarities, there is much greater policy and public awareness of breast cancer than endometriosis. The reasons for this deserve investigation. Why is breast cancer an acceptable topic of conversation and a focus of funding and research? How has breast cancer achieved this place on the agenda? Are there lessons for those advocating for increased awareness of endometriosis and WCPP?

Endometriosis is examined here because it is emerging as a topic of public interest, as was discussed in the previous chapter. One possible cause of WCPP, it is potentially visible and is usually characterised as a disease in a biomedical sense. It therefore seems to have greater potential for agenda advancement than WCPP more generally, or could perhaps serve as a 'flagship' for this greater cause.

Each condition will be outlined before turning to an analysis of the similarities that exist and the reasons for the difference in status now evident in New Zealand and internationally. This chapter demonstrates that these conditions are not only health issues, but political and policy issues also. These conditions have given rise to not only support groups, but advocacy organisations, from which claims can be made on the basis of disease identity, and thus both disease-names are also used as descriptors for these issues more generally.

#### Endometriosis

Endometriosis is a gynaecological and colorectal condition characterised by the presence of endometrial tissue located outside the endometrial cavity, most commonly on the pelvic peritoneum (Perry, 2005; Giudice & Kao, 2004) but also commonly

occurring on the ovaries, in the uterus (adenomyosis), the pouch of Douglas, and bowel and bladder (Trickey & Cooke, 2000). Endometriosis is associated with dysmenorrhoea (period pain); metrorrhagia and menometrorrhagia (irregular menstrual bleeding); menorrhagia (heavy and/or prolonged menstrual bleeding); dysuria (pain of the bladder); dyschezia (pain of the bowel); dyspareunia (pain with sexual intercourse); mittelschmerz (pain with ovulation that worsens over time); and infertility, or may even be asymptomatic (Ballweg, 2004; Stones & Price, 2002; Porpora & Gomel, 1997). Endometriosis patients also commonly report fatigue, nausea, and bloating (Morris, 2006; Henderson & Wood, 2000) (see table 4.1). Complicating this further is that there are a number of other explanations for these symptoms which commonly coexist with endometriosis, such as irritable bowel syndrome (IBS) (Stones & Price, 2002) and interstitial cystitis (IC) (Ingber et al., 2008; Butrick, 2007; Chung et al., 2005, 2002; Stanford, Koziol & Feng, 2005), and still other conditions that can cause similar symptoms to endometriosis in the absence of the disease, such as pelvic inflammatory disease, pelvic congestion syndrome and even muscular complaints (Evans, 2006). Women with endometriosis have also been found to be more likely to have a range of other conditions, including hypothyroidism, fibromyalgia, chronic fatigue syndrome, autoimmune inflammatory disease, allergies, asthma and eczema (Sinaii et al., 2002). While any link to cancer is still uncertain at this stage (Somigliana et al., 2006; Giudice, 2004), Bertelsen et al. (2007) have reported that women with endometriosis are more likely to have breast cancer due to their increased exposure to elevated endogenous oestrogen.

Endometriosis is not necessarily indicated by dysmenorrhoea, which is a common experience, thought to affect up to 80% of women (Bettendorf, 2008). However, advanced disease is commonly linked to this symptom (Milingos et al., 2006), and the term 'secondary dysmenorrhoea' is used for that which results from some organic pathology, like endometriosis (Krotec & Perkins, 2007).

An International Consensus Workshop on endometriosis produced recommendations around issues of diagnosis, classification and prognosis, treatment and outcome, epidemiology and pathophysiology (Rogers et al., 2009). These issues are certainly important ones for endometriosis research, but it is also important to consider how these can ensure better public recognition and agenda visibility of this condition.

Those aspects identified by Birch (2007) as hindering the progression of WCPP onto the agenda, education, empowerment, collaboration, early access and measurement, also need to be addressed.

Table 4.1 Endometriosis symptoms (from Henderson & Wood, 2006)

Symptom	Percentage of women who experienced the symptom
Dysmenorrhoea	82
Pelvic pain	66
Dyspareunia	60
Bloating	59
Lower back pain	57
Ovulation pain	54
Constipation/diarrhoea	52
Fatigue	51
Rectal pain	44
Heavy bleeding	42
Painful bowel movements	38
Premenstrual spotting	31
Frequent urination	31
Infertility	17
Pain when urinating	16

*Prevalence, aetiology, diagnosis, treatment and recurrence*

Endometriosis is estimated to occur in 10% of women of reproductive age, at higher rates in women with fertility problems (Perry, 2005), and has even been found to occur in premenarcheal girls (Marsh & Laufer, 2005). It is the second most common cause of WCPP (after chronic pelvic inflammation) (Szendei et al., 2005), thought to account for between 10-15% of visits to gynaecological clinics (Rikz & Abdalla, 2003). It is estimated to occur in anywhere between 2-74% of women with chronic pelvic pain (Guo & Wang, 2006), and is identified as the cause of pelvic pain in 15-32% of women undergoing diagnostic laparoscopy (Stovall et al., 1997). Increased public and political awareness of endometriosis may thus result in a positive ‘flow-on’ effect for WCPP more generally, as this particular disease may attract the resources needed to achieve political visibility. It would be wise to remember and thus guard against the possibility that it might also obscure this wider claim, as policy around endometriosis will only go so far in alleviating WCPP.

The aetiology of endometriosis is still uncertain, although it is thought to be oestrogen-dependent (Giudice, 2003). This means that while it is commonly understood and treated through the biomedical approach, there is great debate about how this can best be done and what the role of medical professionals ought to be.

One of the most popular theories is that of Sampson (1940) of retrograde menstruation (Vigano et al., 2004), which suggests that there is an increased risk of endometriosis in women with regular and prolonged menstrual flow and an increased 'menstrual insult' to the pelvic milieu (Vercellini et al., 1997). This theory also purports to explain why endometriosis is apparently becoming more common: women now experience more periods than they did in the past (300-400 in a lifetime) and therefore have greater retrograde flow (Thomas, 1993). This negates the more social constructionist position discussed elsewhere, which would suggest that women and medical professionals alike have simply 'discovered' endometriosis and tolerance for the symptoms been lowered.

Others have criticised the theory of retrograde menstruation as unsupported (Arumugam & Lim, 1997) and point out that significant numbers of women must experience retrograde flow without developing endometriosis. Findings of endometriosis in premenarcheal girls also indicate that endometriosis can exist without retrograde flow at all (Marsh & Laufer, 2005). Furthermore, it has been noted that such an explanation does not fit well with instances of findings of endometriosis in remote locations, such as the brain or lung (Murphy, 2002), or with the success of surgical excision in treating symptoms (Redwine, 2002).

Other theories of coelomic metaplasia, and vascular and lymphatic spread, have been criticised for failing to account for the nature and location endometriosis adequately (Bloski & Pierson, 2008). Endometriosis has also been linked to altered immunosurveillance; this idea suggests that the disease is the result of a poorly functioning immune system, suggesting that a normally-functioning immunological system would identify endometrial implants and eliminate them (Christodoulakos et al., 2007; Lebovic, Mueller & Taylor, 2001). Genetic explanations for endometriosis are also being investigated (Nyholt et al., 2009; Giudice, 2003; Taylor, Lundeen and



Giudice, 2002). The implications of genetic components to disease are discussed later in this chapter with regard to breast cancer and genetic screening.

Other factors have also been suggested in the pathogenesis of endometriosis. Associations have been found between endometriosis and risk factors such as higher socioeconomic status, single marital status, early menarche, shorter menstrual cycles with longer duration of flow, dysmenorrhoea, nulliparity, type of contraception, non-smoking status, lack of exercise, cervical conisation, scoliosis, dysplastic nevi, family history of endometriosis, and melanoma (Kuohung et al., 2002), as well as diet (Parazzini et al., 2004), use of oral contraceptives (Parazzini et al., 1999), and reproductive history (Parazzini et al., 1995). Environmental toxins (especially dioxin) have also been asserted to be of causal importance (Capek, 2000), although this has been challenged (Giudice, 2004). Investigation of these kinds of factors indicates that there may be a role for public and environmental health in the understanding and management of endometriosis.

In short, nobody is entirely sure what causes endometriosis, and this is a large part of what makes it such a bewildering condition to have, difficult disease to treat and so problematic as a potential agenda item.

It is also unclear why the presence of endometriosis results in pain. This lack of knowledge may make it difficult for non-sufferers to understand the nature and seriousness of the disease. The description of the action of endometriosis is a useful starting point for an understanding of how the disease causes pain:

“The misplaced tissue responds to ovarian stimulation and, therefore, reacts in the same way as the endometrium throughout the menstrual cycle. Thus, when a woman with endometriosis menstruates, the ectopic endometrial tissue bleeds, usually into places from which the blood cannot escape” (Denny, 2004: p. 641).

Porpora and Gomel (1997) have suggested that endometriosis can invoke mechanisms that provoke pain, such as peritoneal inflammation, infiltration and tissue damage, delivery of chemical mediators of pain, adhesion, and scar formation. Similarly, Stones (2000) has suggested that pain may be caused by increased quantity of

endometrial tissue may influence physiological mechanisms associated with pain sensation during normal menstruation; agents released from endometrial tissue may have direct effects on sensory nerves in the pelvis; adhesions may form, resulting in the distortion and restrict of normal mobility through traction and kinking; or prostaglandin production of the endometrial tissue. It should be noted that other authors have dismissed the role of adhesions in causing pain, although it seems that there may be a relationship with ovarian endometriosis (Parazzini, Mais & Cipriani, 2006). It has also been suggested that persistent nociceptive input from endometriotic tissues leads to central sensitisation in women with endometriosis (Berkley, 2005; Bajaj et al., 2003) and that the divergent sources of pain information converge on central neurons to deliver pain messages (Berkley, Rapkin & Papka, 2005).

Hurd (1998) also suggests that in cases of minimal endometriosis and pelvic pain, the disease is a marker for a physical abnormality responsible for dysmenorrhoea, such as a transverse vaginal septum, noncommunicating uterine horn, stenosis of the endocervical os, patulous tubal ostia, or uterine hypermotility (which would result in more retrograde menstruation). While this may not be able to be resolved, it may guide treatment.

The great problem faced in attempts to understand the relationship between endometriosis and pain is that

“(i)ndividual variability of symptoms is one of the paradoxes of endometriosis. It is not unusual for women with a minimal disease to have severe pelvic symptoms, whereas others with advanced endometriosis are totally asymptomatic” (Dmowski et al., 1997: p. 239).

It is clear that there can be no ‘one-size-fits-all’ approach (Fauconnier & Chapron, 2005), making this condition even more complicated to treat and formulate policy for.

The disconnect between the level of pain experienced and the nature of disease is further complicated by the fact that the current classification system does not match well to patients’ reporting of pain (Gruppo Italiano per lo Studio dell’Endometriosis, 2001; Schenken & Guzick, 1997; Vercellini et al., 1996; Fukaya, Hoshiai & Yajima, 1993). It has been suggested that the mismatch between the stage of disease and

report of pain indicates that in fact different types of disease occur (Dmowski et al., 1997). Nisolle and Donnex (1997) have suggested three distinct forms of endometriosis: superficial peritoneal and ovarian endometriosis; cystic ovarian endometriosis; and, deep infiltrating endometriosis. Location is also thought to be important (Sinaii et al., 2008; Chapron et al., 2003; Stovall et al., 1997) in the nature and intensity of pain experienced.

Some have even suggested that endometriosis (and adenomyosis) should not be understood as a disease at all, but rather, as a normal variant in women (Weiss, 2009; Hurd, 1998; Wardle & Hull, 1993), and that therefore any link to pain is incidental. Hurd (1998) has proposed three criteria by which endometriosis can be marked out as a disease: the nature of pain as cyclic (because the implants are hormonally responsive); surgical diagnosis; and appropriate treatment (i.e. – surgery) should result in prolonged (i.e. – for some months) pain relief. These criteria have been criticised, however, on the basis that endometriosis is more complex than they allowed for, and that noncyclic pain may be attributable to endometriosis, due to central sensitisation, pelvic floor myalgia, vestibulitis or neuropathic pain (Perry, 1999).

Diagnostic efforts are normally made through the public health system, although private health insurance may also cover some patients' procedures. This means that the choice of diagnostic tool is a policy issue as much as a clinical one.

Laparoscopy is the most definitive method of diagnosing endometriosis, and involves what is commonly called 'keyhole surgery', the insertion of a laparoscope through small incisions and, potentially, the removal of disease, usually by laser. Although it is frequently referred to as the 'gold standard' for diagnosis (Khawaja et al., 2009), it has not been immune to criticism as a diagnostic tool, as it is thought to misjudge the extent of disease because of the variety in lesions in terms of size, colour, depth and location (Mettler et al., 2003; Stratton et al., 2003;). It has been found that white and mixed-colour lesions, endometriomas and larger lesions are more likely to be histologically confirmed than black, red or smaller lesions (Stratton et al., 2002). El Bishry, Tselos and Pathi (2008), in their retrospective study of 63 patients in the United Kingdom, reported that endometriosis was histologically confirmed in 75% of

cases, was negative in 18.7% of cases and non-diagnostic in 6.3% of cases. They suggest that positive confirmation depends in part upon the experience of the pathologist.

Tools other than laparoscopy are also used to help make a diagnosis of endometriosis. Ultrasound is commonly used as a preliminary investigation for endometriosis, and has been found to reliably predict ovarian endometriosis (Eskenazi et al., 2001), with transvaginal ultrasound being accepted as a useful way to make and exclude the diagnosis of ovarian endometrioma (Moore et al., 2002). Magnetic resource imaging (MRI) has even been suggested as a diagnostic tool, but dismissed as it is not cost-effective, pelvic fluid may obscure visibility and there is a lack of specificity (Stratton et al., 2003). Neither of these tools is considered sufficient in themselves to either make or rule out a diagnosis. Other non-invasive strategies are also being evaluated for diagnostic potential (although with a focus on endometriosis-associated infertility) such as serum and endometrial markings, which are thought to hold great potential to revolutionise the diagnosis of this disease (Brosens et al., 2003).

Clinical examination is also thought to be useful, if not necessarily in making a diagnosis, then at least in determining the necessity of further investigation. Garry (2006) has reported that abnormal findings on pelvic examination correspond with finding of disease in 70-90% of cases, but also warns that in more than 50% of cases where disease is found with laparoscopy, examination findings were normal. Garry notes that history-taking is also thought to be a poor discriminator but is usually recommended, as there is evidence of a hereditary link (Kuohung et al., 2002) and it is considered important that a woman be given the opportunity to tell her story (Vincent, 2009). There may also be clues in the consultation that point to other associated conditions (Paulson & Delgado, 2007).

The role of clinical experience (the 'experiential credential') is often emphasised also; this model of clinical practice or clinical judgment "attends to the idiosyncrasies of individual patient cases by drawing upon practitioner experience, sympathy, careful attention to the patient account, and intuition" (Whelan, 2009: p. 1). In this way, it serves to compensate for the limits of medico-scientific understanding of endometriosis (Whelan, 2009) and preserve the authority of the medical practitioner,

rather than ceding it to histologist or pathologist (Whelan, 2009). This kind of clinical experience consists of specific skills, observations made over time, actual findings and background knowledge gained in clinical practice (Whelan, 2009).

Diagnostic delay is widely considered one of the most troubling aspects of endometriosis, particularly as the disease is progressive (Endometriosis New Zealand, 2009; Garry, 2006; Matsuzaki et al., 2006; Husby, Haugen & Moen, 2003). The variety and complexity of the disease is a major problem in diagnosis, and should be considered a major contributing factor to the problem of diagnostic delay (Greene et al., 2008). Diagnostic delay in the United States averages 11.7 years, and, in the United Kingdom, 8 years (Hadfield et al., 1996). In New Zealand, it has been estimated at 10 years (Endometriosis New Zealand, 2009). Delay has been found to be longer in those women experiencing pelvic pain as the primary symptom (rather than infertility) (Arruda et al., 2003).

Diagnostic delay comprises both the delay in the patient seeking medical help, and the delay involved in getting a diagnosis within the medical system. It has been suggested that the length of each is roughly equivalent (Greene et al., 2008). Ballard, Lowton and Wright (2006b) emphasise the influence of patients, particularly the tendency to normalise their experience (especially if they had had 'difficult' periods since menarche) and the inability to distinguish between 'normal' and 'abnormal' menstrual experiences, as well as concerns about disclosure with feelings of embarrassment or of not wanting to be seen as weak and unable to cope. Santer, Wyke and Werner (2008) suggest that women may also self-manage their symptoms, through limiting activity, analgesia, rest, application of heat, massage, exercise etc.

Denny & Mann (2008) have discussed the problem of medical delay, and identify that this is more likely to occur in primary care than in secondary, perhaps because the symptoms of endometriosis do not present in ways that general practitioners are accustomed and because the symptoms usually occur around menstruation, and are therefore easily dismissed, or normalised as 'just' period pain.

Scambler and Scambler's 1985 investigation into consulting behaviour for menstrual problems has provided a typology of non-consulters. 35% of those surveyed were

classified as 'unaffected'; they did not experience distress nor see menstruation as a health problem. 22% were classified as 'alienated'; they experienced high symptom distress, often held antipathetic attitudes towards menstruation, but did not consult, believing that medicine could not help them, or because of bad experiences in the past. 'Realists' accounted for 17% of those surveyed; they did not experience symptom distress, but did see periods as a potential health problem. Finally, 15% were classified as marginals who expected high symptom distress levels, but did not define menstruation as a health problem. This illustrates that simply because women are not consulting for menstrual problems, does not mean that they are not experiencing them, and that consultation rates are not sufficient data from which to draw conclusions about prevalence. It also indicates a rejection of biomedical explanations for menstrual problems, with some women suggesting that biomedicine was not the approach lens with which to understand menstruation, that biomedical approaches could not help them, or that biomedicine's practitioners had somehow failed them.

Attitudes like these may inhibit consultation for menstrual problems, but there is also a significant medical diagnostic delay. Ballard, Lowton and Wright (2006b) suggested that this may occur due to dismissal or normalisation by primary care physicians, intermittent hormonal suppression of symptoms (either by pregnancy or medication, or the use of non-discriminatory investigations that may provide false-negatives (e.g. – ultrasound). Stratton (2006) has added also that physicians tend to discount the possibility of endometriosis in adolescent patients (a problem that will be turned to later in this chapter).

There are some official treatment guidelines available. Those of note are those from the Royal College of Obstetricians and Gynaecologists (RCOG), the American College of Obstetricians and Gynaecologists (ACOG) and European Society for Human Reproduction and Embryology (ESHRE) Special Interest Group for Endometriosis. (As yet, there are no such guidelines that apply in New Zealand.) These all acknowledge the possibility of medical treatment without an actual diagnosis of endometriosis (which can only be definitively made by surgical intervention). This is supported by the work of Gambone et al. (2002), who have stated that surgical confirmation of disease is unnecessary and suggest that there is

inadequate evidence to support other surgical interventions such as uterosacral nerve ablation or hysterectomy (Gambone, 2002). Pugsley and Ballard (2007), acknowledging the dangers of over-investigation, have suggested that general practitioners use a 'working diagnosis', communicated to the patient, that allows for the initial use of hormonal therapies. A provisional diagnosis may be useful (Ballard, Lowton & Wright, 2006a) and a term such as 'hormonally-responsive gynaecologic pain' may be applied in the interim (Kennedy, 2006).

The aim of treatment of endometriosis is usually held to be the relief of symptoms (Deb, 2008), to increase the possibility of pregnancy and delay recurrence (Donnez et al., 2004). This is not as straightforward as it may seem: as mentioned in the previous chapter, women may not necessarily be seeking symptom relief, but firstly (or even, only) an explanation of their experiences (Grace, 1995). What is more, medical therapy may not diminish endometriosis lesions and therefore leave women vulnerable to other complications, such as infertility, although it may control their symptoms adequately. A number of therapies are being considered in the treatment of endometriosis; Botulinum Toxin (Botox) has even been mooted as a possible therapy for the future (Abbott, 2009).

The treatment guidelines noted above suggest that hormonal treatments (such as progestins, danazol, gonadotropin-releasing hormone (GnRH) agonists, oral contraceptives and levonorgestrel uterine system (LNG-IUS)) (Vincent, 2009), most of which induce a hypoestrogenic state (Nothnick & Zhang, 2009) and pain medications (non-steroidal anti-inflammatory drugs (NSAIDs), particularly COX-2 inhibitors that inhibit prostaglandin production) may help to relieve symptoms. Many of these hormonal treatments are considered to be relatively similar in terms of efficacy, although they differ in terms of side effects (Ozkan & Arici, 2009; Wood, 2001).

As well as being important in diagnosis, laparoscopy may also serve to facilitate treatment in both endometriosis and WCPP (Milingos et al., 2003; Porpora & Gomel, 1997). This double function makes it extremely useful. It is thought that around 40% of laparoscopies occur for chronic pelvic pain (Howard, 1993). While commonly regarded as an effective means of treatment (Kaiser et al., 2009), estimates of success

rates of laparoscopic surgery, in terms of a positive diagnosis, seem to vary. Porpora and Gomel (1997) put the rate at 60%, while Abbott et al. (2004) suggest that the failure rate may be as high as 20%. Wykes et al. (2006) found that 67% of women reported improvement in pain symptoms following laparoscopy. Assessing success rates in terms of positive outcome is more problematic still, due to the problem of recurrence and that patients' understanding of success may be different to their surgeon's: 'negative' findings may have positive outcomes for patients, who may feel reassured and be able to pursue other avenues for relief (Porpora & Gomel, 1997), or 'positive' findings may not result in symptom relief.

Because of the shortcomings of laparoscopy as a diagnostic tool, there are automatic concerns with it as a means of treatment; if the disease cannot be seen, it cannot be excised. It is commonly accepted that endometriosis may exist without it being laparoscopically detectable even if it is histologically detectable (Arumugam & Lim, 1997) and the importance of histological diagnosis has been emphasised (Wright, Shafik & Ratcliffe, 2002).

The levonorgestrel-releasing intrauterine system (LNG-IUS), commonly marketed under the name 'Mirena', is a form of contraceptive device heralded as a treatment for endometriosis and related conditions such as adenomyosis (Bahamondes et al., 2007; McGavigan & Cameron, 2003). The Mirena is purported to be a safe, efficacious, long-term (five year) contraceptive device and commonly reduces menstrual blood loss (McGavigan & Cameron, 2003). This reduction in blood loss may be welcomed or rejected by women (Thomas, 2000; Ellerston, 1999). It is considered particularly beneficial because, unlike most hormonal treatments, it is thought to act to *reduce* endometrial lesions, rather than just suppressing further growth (Phillips et al., 2003). Robinson et al. reported that less than 5% of women required subsequent surgical treatment for menstrual disorders following the insertion of a Mirena (Robinson et al., 2008). In their investigation of its cost-effectiveness, Varney and Guest (2004) emphasised that, while cost-effective, it is also important to consider user acceptability and quality of life, and difficult to factor these considerations into an evaluation of cost-effectiveness.



Studies of patient satisfaction with the Mirena often contradict each other. Robinson et al., 2008, reported a mean satisfaction rating of 7.07/10, and Baldaszti, Wimmer-Puchinger and Loschke, 2003, reported that after 36 months 77% of women reported being 'very satisfied' with the Mirena). However, Daud and Ewies (2006) report that 46% of their sample removed the Mirena within 3 years of insertion due to adverse side effects, particularly 'breakthrough' bleeding (or spotting), abdominal pain, and progestogenic effects (e.g. – bloating, headache, weight gain, depression, breast tenderness, excessive hairiness, greasiness of skin, and lack of sexual interest). McGavigan and Cameron (2003) have also noted the problem of irregular bleeding (the cause of which is not well understood) and high rates of discontinuation due to this (McGavigan & Cameron, 2003).

Other nonpharmaceutical measures are sometimes used in the treatment and management of endometriosis symptoms, including physiotherapy, psychological therapy (e.g. – cognitive behavioural therapy), chiropractic treatments, osteopathy, acupuncture, naturopathy and TENS machines (Vincent, 2009; Molloy, 2006).

One of the major issues in the treatment of endometriosis is the problem of recurrence (of both disease and symptoms). Guo (2009) has reported recurrence of disease at 21.5% at 2 years and 40-50% at 5 years (following laparoscopy); while Porpora et al. (2008) found that pain recurred in 14.5% of women after three years. In a small percentage of women, pain may even worsen (Vercellini et al., 2009b). Shakiba et al. (2008) found the reoperation rate in women undergoing laparoscopy was 21.2% at 2 years, and 36% amongst 19-29 year-old women; this increased likelihood of recurrence at an older age is also noted by Parazzini et al., 2005. Porpora et al. (2008) reported the recurrence of dysmenorrhoea at 14.5%, and chronic pelvic pain at 5.4% after 5 years. Requirement of repeat surgery has been estimated at 25% (Vercellini et al., 2009a), and is thought to be higher in women with colorectal symptoms (Falcone et al., 2000) or interstitial cystitis (Ingber, 2008). It is worth noting that the amount of 'surgery-free' time cannot be predicted by the stage of disease found at laparoscopy, another indication of the shortcomings of the current classification model (Shakiba et al., 2008).

Recurrence is thought to occur at, or close to, the original site, and thus likely be due to either incomplete excision at initial surgery (Taylor & Williams, 2008). Another possibility when pain persists after surgical excision of disease is that adenomyosis (disease within the uterine wall) is responsible for the pain (Parker et al., 2006). Recurrence of disease is also thought to be operator-dependent to some extent (Vercellini et al., 2009a).

High rates of recurrence have led to calls for endometriosis to be treated with a combination of surgical and medical interventions (Huang, 2008). This would involve excision of disease surgically, and then medical management to try to control any further disease. Pregnancy is also thought to have a protective effect on disease and pain recurrence (Porpora et al., 2008).

The problem of recurrence is a difficult one from a policy perspective. While the burden of endometriosis might come to be understood as sufficient to justify policy action, if there is no effective (and lasting) treatment, the lack of policy solution may inhibit its political potential.

### *Impact of endometriosis*

As might be expected when it is so prevalent, endometriosis represents a significant cost to the health system and wider society. The annual cost of endometriosis to the United States' health system was estimated at between \$18.8b and \$22b in 2002 (Rogers et al., 2009), while gynaecologist visits were estimated at \$128.9m annually (Gao et al., 2006). There is no clear data on indirect costs, but it is reasonable to assume that the figures suggested for WCPP in Chapter 1 (p. 3) earlier are similar, given the commonality of symptoms. It is important to note Grace and Zondervan's 2006 findings that women who reported activity-restriction did not take more time off paid employment than women without pelvic pain.

The impact of endometriosis on a woman's life and that of her family cannot be accounted for in economic terms. As has already been discussed with regard to WCPP more generally, chronic illness is a difficult experience. Furthermore, Mathias et al. (1996) have reported that of chronic pelvic pain patients, endometriosis patients report

the greatest interference with activities because of pain, the most health distress, and the highest score for pain during sexual intercourse. For women continuing to experience pain from endometriosis following treatment, the future may be viewed with great pessimism, due to concerns about their ability (and that of their partners and families) to cope with the disease (Denny, 2004). Women may also struggle to explain and legitimate their condition in the face of lack of knowledge and support from others and differing medical perspectives (Whelan, 2007).

Huntington and Gilmour (2005) have identified four themes in women's experiences with endometriosis: that of manifestations of pain, where pain was described as severe and diffuse, with both physical and psychological dimensions; of pain trajectory, where pain fluctuated according to factors such as menstruation or treatment, and peaked and waned in recurring patterns; of treatment, which was often life-disrupting and ineffective; and of controlling and adapting to the pain, which required lifestyle and attitude changes were needed, and there was an identification of the importance of agency and control. Similarly, Gilmour, Huntington and Wilson (2008) have described three common experiences in women's descriptions of endometriosis: disclosing symptoms, as the condition was experienced as deeply private and not easily disclosed, affecting everyday functioning; of interrupted life, as symptoms (especially pain and fatigue) impacted upon women's social and work lives; and re-emergence as women began searching for alternative treatments and self-management strategies and acknowledged necessary lifestyle changes.

The impact of endometriosis may also be felt in emotional and psychological terms. Although, as noted in the previous chapter, these may be seen to either contribute to the chronic pain or result from it (Goudsmit, 1994), it is well documented that psychiatric morbidity, particularly in the form of depression and anxiety, often coincide with pelvic pain conditions (Clemens, Brown & Calhoun, 2008; Peveler, 1996).

### *Endometriosis in Adolescents*

Although it was once assumed that endometriosis only occurred in women well into their reproductive lives, it is now firmly established that endometriosis may occur in

adolescents, and is in fact the leading cause of chronic pelvic pain in adolescents (Sanfilippo & Erb, 2008; Attaran, Falcone & Goldberg, 2002). Zondervan et al., (1999) have shown that women in the 31-40 age bracket were approximately twice as likely as those in the 13-20 or 61-71 age brackets to have been referred to a gynaecologist.

Adolescents may present a different problem to adult patients: they usually present with pain (whereas adult patients often present with fertility concerns) (ACOG Committee on Adolescent Health Care, 2005). Laufer (2008) acknowledges that treatment of this group can be particularly difficult, and will normally focus on menstrual suppression (through hormonal therapies). Only treatments that preserve fertility options are considered acceptable (ACOG Committee on Adolescent Health Care, 2005) and the goal of treatment can be expressed in terms of three different elements of concern the disease may raise: suppression of pain, suppression of disease progression, and preservation of fertility (ACOG Committee on Adolescent Health Care, 2005).

Endometriosis in adolescents may be an even more serious problem. Stratton (2006) has noted that 70% of endometriosis patients report symptoms beginning before age twenty, and nearly 40% before age fifteen. Greene et al. (2008) have reported that adolescents wait longer both to consult and get a diagnosis, and that adolescents are more likely to report their symptoms being dismissed by their physicians. Ballweg (2004) has reported that early onset endometriosis is more severe. Laufer (2008) has argued for the importance of early diagnosis in order to prevent disease progression and preserve future fertility, while Solnik (2006) suggests that early intervention may result to better pain management.

The ACOG paper issued on endometriosis in adolescence stated that if an adolescent does not get symptom relief from hormone therapy and NSAIDs, endometriosis should be suspected and laparoscopy should be offered (ACOG Committee on Adolescent Health Care, 2005). GnRH agonists are not regularly prescribed to this age group due to concerns about bone density, although some have claimed that GnRH agonists can be safely given to adolescents provided add-back therapy is also provided (Laufer, 2008).

Endometriosis, at any age, is clearly a complex condition that is troubling to those suffering from it, their partners and families, as well as the medical profession, health system, and policymakers.

### Breast cancer

A comparative analysis of breast cancer serves to highlight the different trajectories of these two women's health issues. Breast cancer is the leading cause of cancer death in New Zealand women (Harman et al., 2002): over 600 women die each year from breast cancer in New Zealand (New Zealand Breast Cancer Foundation, 2009; New Zealand Health Information Service, 2002). It is also estimated that over 40,000 women will die from the disease in the United States in 2009 (National Cancer Institute, 2009).

Breast cancer is also highly prevalent; in New Zealand, women have a 1 in 9 chance of being diagnosed with breast cancer at some point in their lives (in Australia and the United Kingdom, this figure is 1 in 8; in the United States, 1 in 7) (NZBCF, 2009). The number of women being diagnosed with breast cancer in New Zealand is increasing yearly, from 1865 in 1995 to 2361 in 2004. Deaths resulting have remained steady, with somewhere between 600-650 deaths being recorded annually across this time (see Table 4.2). New Zealand has the sixth highest mortality rate for (female) breast cancer amongst OECD countries (NZHIS, 2002).

Table 4.2: Breast Cancer Diagnoses and Deaths, 1995-2004 (NZBCF, 2009).

<b>Year</b>	<b>Diagnosed</b>	<b>Deaths</b>
1995	1865	638
1996	1906	631
1997	1990	620
1998	2071	629
1999	2248	646
2000	2300	622
2001	2310	617
2002	2345	625
2003	2297	647
2004	2361	646

Although there is no clear biomedical explanation for breast cancer, with suspected determinants or risk factors ranging from reproductive factors (e.g. – breastfeeding and multiple, both of which have been hypothesised to reduce risk) to lifestyle factors (e.g. – low fat intake and high physical activity levels are thought to reduce risk), to hormonal factors (e.g. – the use of oral contraceptives are thought to heighten risk in the short-term) (Alberg & Helzlsouer, 1997)), breast cancer is regarded as a biomedical issue.

The New Zealand Cancer Control Strategy (2003) describes a continuum of care for breast cancer: prevention, early detection and screening, diagnosis and treatment, support and rehabilitation, and palliative care (Minister of Health, 2003).

### *Treatment and management*

There are clear actions that can be taken to reduce the impact of the disease, most notably routine screening and medical therapies. The NHC has established criteria for New Zealand that guide when a screening programme is indicated: the suitability of the condition for screening, existence of a suitable test, availability of effective treatment, high quality evidence that a screening programme is effective in reducing mortality or morbidity, potential benefits outweigh the potential for harm, capability of the health care system to complete the screening pathway, consideration of social and ethical issues and cost-benefit issues (NHC, 2003).

It is important to note that although screening has raised incidence rates (Richardson, 2005, 2004), screening is not the whole answer; only about 30% of tumours are thought to be detectable by mammography, and it is best at detecting slow-growing tumours (Love, 2007).

Prior to 2004, BreastScreen Aotearoa provided free breast screening (in the form of a mammogram) for women between the ages of 50-64. This age band represented the group at highest risk of breast cancer (Baker, Wall & Bloomfield, 2005), where changes in breast tissue following menopause make detection easier in women of this age group (compared to pre-menopausal women), while also protecting younger women against the potentially harmful effects of radiation exposure (cancerbackup,

2009). It has been estimated, however, that only one-third of women who developed breast cancer were being screened prior to 2004 (Harman et al., 2002) and the extension of the age eligibility criteria to 45-69 by the then Labour-led government (King, 2004).

Sentence

It is of some concern that women are required to opt in to this service initially (Bowling, 1989) although if they have been screened before, they will be sent a letter when it is time for them to be rescreened (which occurs at two year intervals) (National Screening Institute (N.Z.), 2009a).

The Cancer Society recommends that women who are not be eligible for the BreastScreen Aotearoa programme on age grounds, but have a strong family history of breast cancer, previous breast cancer, or detection of a risk lesion (atypical hyperplasia), still receive regular mammograms (Cancer Society (N.Z.), 2003).

A National Cancer Registry has also been established (Armstrong & Borman, 1996) which is helpful in terms of identifying trends in the data and tailoring services to fit. However, in terms of breast cancer at least, this registry has been criticised as lacking accurate information about the stage of disease, details of treatment, outcome data (especially on response rates and duration), comparative data and occupational and exposure data (Spearing, 2007).

### *Funding of Herceptin*

The recent history of breast cancer in New Zealand is intimately tied to the drug Herceptin. The struggle for Herceptin to be publicly funded is an important example of how, even once an issue has achieved prominence, the agenda-setting process is ongoing, always incomplete.

Historically, treatment has occurred through the public health system, but with the last decade of the twentieth century came a sharp increase in the number of treatments available, raising issues of affordability (Harvey, 2007).

Herceptin (trastuzumab) is an antibody developed to target the HER2 receptor, which is responsible for controlling the growth and repair of cells. HER2 is over-expressed by some cancer cells, and the drug is designed to inhibit the proliferation of those tumour cells that over-express HER2 (Orman & Perry, 2007; Plosker & Keam, 2006), thought to occur in between 20-25% of breast cancer (McKeage & Perry, 2002). It has been available in New Zealand for advanced (metastatic) cancer since 2001 (Rosevear, 2006). Costing between \$70,000-\$120,000 per patient, the funding and availability of Herceptin for early HER2-positive breast cancer has been a hotly debated issue in New Zealand and internationally. In New Zealand in 2005, a petition was presented to the then Labour-led government on the issue, carrying 18,600 signatures and calling for the immediate full funding of Herceptin (Burgess, 2006; BreastCancer.org, 2005).

Indications are that Herceptin, used as an adjuvant treatment in early HER-2 positive breast cancer after chemotherapy, improves disease-free survival after 2 years from 77.4% to 85.8% (McKeage & Lyseng-Williamson, 2008; Rosevear, 2006).

The Pharmaceutical Management Agency (PHARMAC) is the Crown entity (reporting to the Ministry of Health) responsible, amongst other things, for the Pharmaceutical Schedule, the list of pharmaceuticals that are publicly funded. The agency's statutory objective is:

“to secure for eligible people in need of pharmaceuticals, the best health outcomes that are reasonably achievable from pharmaceutical treatment and from within the amount of funding provided”  
(PHARMAC, 2009)

PHARMAC relies upon its clinical advisory body, the Pharmaceutical and Therapeutics Advisory Committee (PTAC) for clinical information on pharmaceuticals, as well as an established consultation process (Metcalf, Evans & Priest, 2007) and nine decision criteria to assess when allocating funds to pharmaceuticals: the health needs of all eligible people within New Zealand; the particular health needs of Maori and Pacific people; the availability and suitability of existing medicines, therapeutic medical devices and related products and related things; the clinical benefits and risks of pharmaceuticals; the cost-effectiveness of



meeting public health needs by funding pharmaceuticals rather than using other publicly funded health and disability support services; the budgetary impact (in terms of the pharmaceutical budget and Government's overall health budget) of any changes to the Schedule; the direct cost to health service users; the Government's priorities for health funding, as set out in any objectives notified by the Crown to PHARMAC, or in PHARMAC's Funding Agreement, or elsewhere; and, such other criteria as PHARMAC thinks fit. PHARMAC will carry out appropriate consultation when it intends to take such 'other criteria' into account (PHARMAC, 2006).

In May 2007 PHARMAC announced it would fund a nine week course of Herceptin for women with HER-2 positive breast cancer (PHARMAC, 2008b), at a cost of \$6m (NZBCF, 2007). There was considerable support for this decision; the nine week course was held to be practicable (DHBs indicated they were able to provide services) and relatively cost-effective (at an estimated \$14,500-\$16,500/QALY), while giving comparable results to longer-duration treatments (Metcalf, Evans & Priest, 2007). There were also concerns at the possible toxic effects of longer-term treatment, particularly cardiotoxicity (Rosevear, 2006; McKeage, 2002).

However, many remained concerned at the lack of funding for a 12 month course, and public outcry turned this into an election issue in the 2008 national elections (Breast Cancer Aotearoa Coalition, 2008). Following the change of government to a National-led government in the November election, funding of a 12 month course was announced in December 2008 for those patients whose doctors recommended it (Key, 2008), estimated to be around 300 patients (NZBCF, 2008), at an estimated cost of \$25m (NZBCF, 2007). Those who had begun this treatment prior to the announcement are also able to apply for reimbursement (Ryall, 2008).

The question of Herceptin funding indicates that public awareness of an issue can do much to ensure political awareness of an issue. The funding of Herceptin was undoubtedly influenced by a vocal minority, the activity of various interest groups, and the media response to these advocates. The 2008 election also served as a 'policy window' (Kingdon, 1995 [1984]), in which there was opportunity for change; and indeed, the National Party used this as an election issue.

As has been discussed with regard to medicalisation, one of the concerns in terms of the Herceptin question is that pharmaceutical companies are able to manipulate patients and governments. The Managing Director of Roche in New Zealand responded in the *New Zealand Medical Journal* to an article expressing concerns at the cost of Herceptin by saying: "It is important that the real benefit adjuvant Herceptin offers for women with HER2-positive early breast cancer does not get lost in the debate over the costs of providing this treatment" (Petersen, 2006: p. 2). While this is the same point made by countless others across a number of fields, the pharmaceutical industry has a vested interest (in the form of profits and market share) in appearing to value the lives of patients over the costs of treatment provision, even if the calculation could be seen as so uncomplicated (Gosden & Beder, 2001).

As Lerner (2001) has emphasised of breast cancer treatment generally,

"(a)lthough we may intuitively associate more aggressive action with better outcomes, this only occurs in some instances. A woman with breast cancer may be able to influence her fate. But in other cases... 'extra' treatment may provide minimal or no advantages. As much as we want it to be true, there is no guaranteed *quid pro quo*" (p. 296).

Gathering data on treatments may also be difficult; while women faced with their own mortality may be willing to participate in clinical trials, there are a number of ethical issues with attempting to evaluate the relative effectiveness of treatments such as prophylactic surgery and chemoprevention, most obviously that it restricts the patient from trying another course of treatment (Tambor et al., 2000).

What has happened in New Zealand, at least, is a push for women, their families and their doctors, to be able to make decisions regarding treatment. This places high value on patient participation, which may be considered appropriate when dealing with potentially fatal conditions and high stakes outcomes.

### *The genetic link*

Screening and treatment cannot be considered truly preventive: the former aims for early detection, the latter for elimination and amelioration; neither has the capacity to

*prevent* disease, though they may improve outcomes. Genetic testing (for the BRAC1 and BRAC2 gene mutations) has been heralded as potentially providing something closer to preventive action, through what is termed predictive genetic testing (NHC, 2003). This mutation is linked to both breast and ovarian cancers, with an 85% risk for breast cancer (BreastCancer.org, 2008) and 65% for ovarian cancer for those with the mutation (NHC, 2003). This gene has been identified within 1-5% of diagnosed women in New Zealand (NZBCF, 2009). Breast cancer in younger women is more often attributable to the genetic mutation (Winship, 2007), and it can therefore be argued that genetic testing is particularly important in younger women, as breast cancer may otherwise not be detected until it is too late.

Testing occurs in the form of a blood test, and might be considered in women with a family history of breast cancer (those with a family history of breast cancer are considered at higher risk, regardless of whether they possess the gene mutation). The Northern Regional Genetic Service (in Auckland) and the Central and Southern Regional Genetics Service (in Wellington and Christchurch) provide services such as genetic testing and counselling, normally free of charge (Health Point, 2009). These tests can otherwise cost between \$300 and \$3000 dollars.

The type of action that can be taken in the event of a positive test is still decidedly limited, particularly as the presence of the mutation is not sufficient to definitively predict disease but only to identify a heightened risk. Thus, a surveillance plan (regular mammograms and self-examination) and possibly some lifestyle adjustments (e.g. – exercise) may be recommended. Prophylactic strategies may be undertaken by some women upon discovering their genetic predisposition, including the use of tamoxifen, thought to reduce risk of getting breast cancer by 30-50% (but associated with many side effects, including increased risk of endometrial cancer); oophorectomy (removal of the ovaries), which has a similar risk reduction rate to tamoxifen, but removes the need for ovarian surveillance, considered imprecise; and mastectomy, thought to reduce risk by up to 90% (The Breast Centre, 2009).

Genetic testing thus provides a less than ideal means to controlling breast cancer. Surgical intervention is obviously undesirable, if only for the risks it places women under. What is more, the identification of the gene mutation can often be viewed as

determining, which, although mistaken, may lead to discrimination and stigmatisation by others (Lerner, 2002), as well as fear on the part of the individual and those close to them. Giddens (1991) has described risk estimation as the 'colonisation of the future' and certainly the knowledge of such a genetic predisposition can be difficult to live with. Hallowell (2006) has investigated what it is like to 'live with risk' of ovarian cancer, and has described it as:

“a matter of life and death...about living with the memory of other's suffering...making sure the future did not recapitulate the past... saving oneself from pain and sparing others from witnessing agony... about avoiding death so one could nurture others' lives...about fear, loss, illness, disease, self and others, but primarily...about avoiding suffering and staying alive” (p. 23).

To live with risk is to live with uncertainty. The use of genetic testing means that the individual may become an 'unpatient', one who has no apparent disease but is a subject of the medical system (Jonsen et al., 1996), in a 'potential sick role' (Crawford, 1980). The individual may also be 'geneticised' (Novas & Rose, 2000), building their genetic inheritance into their identity and potentially seeing the self as uncertain also.

The possibility of genetic testing is a tricky problem not just for individuals, but also for medical professionals and policymakers (Lerner, 2001). Beyond the problem of whether (and which) genetic tests should be publicly funded, as with other genetic conditions, there is the risk that women could be considered to have a *responsibility* to be tested and take 'appropriate' action, with failure to do so resulting in sanctions such as the loss of health insurance, financial support, sympathy and so on. The term 'test' connotes a 'pass' or 'fail' result, and so to 'fail' could potentially become seen as deviant (Crawford, 1980). It is also unclear whether results of genetic tests should be made available to others, such as blood relatives, insurance companies and employers. In the same way as medical therapies may be viewed cynically due to the interest of the pharmaceutical industry, so must genetic testing be viewed with caution due to the interest of biotechnology companies.

Much work remains to be done on genetic testing at a policy level, as there is a lack of assessment of genetic testing in this country, no advisory body to recommend which tests should be publicly funded, no criteria for assessing when tests are ready for public use, and no coordinated mechanism to develop and assess new tests (NHC, 2003).

### Why has breast cancer managed to achieve prominence when endometriosis has not?

Both endometriosis and breast cancer can be understood as chronic conditions; pain and other symptoms may not be constant, but certainly recurrent, and may result in functional impairment (the inability to carry out everyday tasks) (Chirikos, Russell-Jacobs & Jacobsen, 2002). They are both intimately linked to the nature of the patient as *woman*; both breast and the reproductive organs are obviously intensely *female*. This means that issues of gender discrimination discussed in the previous chapter are often encountered. This may be part of the reason that phenomenological studies indicate similar patterns of illness experience (Greenslade & House, 2006; Huntington & Gilmour, 2005).

In the same way, both women's breasts and reproductive organs can be understood as having been medicalised. Ferguson (2000) has discussed how women's breasts have been medicalised, and that through procedures like augmentation and reconstruction, "physicians have exercised social control over women, by keeping women in doctors' offices and on surgeons' tables for procedures that are not medically necessary" (p. 69). It is important to realise, however, that breast reconstruction following mastectomy can also be understood as empowering for women and helpful in protecting their personal identity. Similarly, suggestions that endometriosis is not a disease but a normal occurrence, are in part claims that women's reproductive processes and bodies have been medicalised to the point that 'normal' processes are thought to be pathological.

These two diseases are also similar in that, although there is identifiable pathology, they are imperfectly understood within biomedicine and imply a *condition* that extends beyond the symptoms directly attributable to the disease itself. Both endometriosis and breast cancer are likely to highlight the shortcomings of

biomedicine to women, at the same time as the seriousness of the disease is likely to push them towards dependence upon biomedicine (Abel, 1998). Often too, other models are turned to. Both have embraced the environmental health paradigm, with the Endometriosis Association in the United States being influential in positing the so-called 'dioxin connection' (Capek, 2000) and the Environmental Breast Cancer Movement similarly highlighting environmental toxins.

The two are also similar in raising the concern that practitioners' expertise may be so considered so important that their values are imprinted upon women. Cowley et al. (2000) note that medical professionals may wish to 'protect' women from fully informing women about disease, but that this may allow misconceptions to form that are also dangerous. This also seems to compromise the patient's right to information and their sovereignty over their own body.

As causes, both are plagued by similar problems, namely that of where energy is best focussed. Many organisations working on these issues are focussed on ensuring research. Certainly this is important; without sufficient research, these diseases will remain poorly understood, and more efficacious treatments will not be unearthed (Sharpe-Timms & Young, 2004). However, research can never be the whole answer. Such organisations might also undertake to provide support, distribute information and raise public and policy awareness of these issues. Both also require good clinical care, and the health services to provide this, meaning that health reform may also be a point of focus (Shaffer, 2000).

What is immediately obvious when considering these two women's health issues is that there is apparently more that can be *done* for breast cancer, particularly in the way of screening. There is no practicable means by which to screen for endometriosis, and while Fauconnier & Chapron (2005) have called for severe dysmenorrhoea to be considered as a 'screening tool', arguing that the presence of severe pain should be sufficient to encourage laparoscopy, there is no simple means of early detection in the same way that is available for breast cancer. What is more, the condition does not fit the criteria from the NHC (2003) laid out earlier in this chapter. Endometriosis, with its amorphous symptoms, inadequate classification system, and lack of efficacious

treatment has trouble satisfying criteria for a screening programme (Evers, Dunselman & Van Der Linden, 1993).

More importantly still, in terms of the awareness and resources breast cancer is able to raise, is that it is a life-threatening condition. However, it is worth considering other types of cancer affecting women that do not get such support: ovarian cancer kills around 175 women every year; uterine cancer, around 80 women; and cervical cancer, around 65 women (Silver Ribbon Foundation for gynaecological cancer (N.Z.), 2009), as this indicates that mortality rates alone are not sufficient to arouse the type of support that breast cancer has been successful in doing.

One problem may be that of single-issue policymaking, which may have emerged around breast cancer, particularly in the United States. This

“encourages competition among diverse health advocacy and interest groups for limited resources...can arouse opposition to such policy options as earmarked research funding that are perceived as taking resources away from other important health problems...contribute to the fragmentation of women’s health care services by focusing attention on one disease or body part rather than on social conditions or services that promote overall health...(and therefore) can detract attention and resources from a broader women’s health agenda” (Weisman, 2000: p. 238).

One of the most crucial elements in explaining the status difference in these two conditions is the success of breast cancer activism.

### *Breast Cancer Activism*

Despite mortality rates, prevalence and the measures available, the attention given to breast cancer is relatively new. In fact, breast cancer is in many ways a prime example of the results activism can have on a health issue.

Brendtro (1998), in her examination of breast cancer’s rise to prominence, explains that:

“Political activism became a way for women with breast cancer to address their frustration with the insensitivity many had experienced at the hand of the medical establishment and with the lack of funding needed to make significant strides in the control of breast cancer” (p. 57).

Breast cancer activism has garnered much of its strength and momentum from the women’s movement that began in the 1960’s (Morgen, 2002). The breast cancer movement (BCM) is rooted in feminist ideals, that the ‘personal is the political’ (McCormick, Brown & Zavestoski, 2003; Wilkinson & Kitzinger, 1994) and the claim of “the inadequacy of the patriarchal medical profession to understand a breast cancer experience that is deeply rooted in being a woman” (Morello-Frosch, 2006: p. 258). An explicitly feminist approach to breast cancer has been advocated by Wilkinson and Kitzinger (1994), who claim that, while they are not “simply suggesting the substitution of sisterhood for surgery” it is important that women do not accept “male definitions of our ‘femininity’ and sexuality, or victim-blaming fantasies of omnipotence over the cause of our disease” (p. 135). Furthermore, they claim:

“we cannot stop at theory: we need to develop feminist practice around breast cancer, through, for example, political lobbying and the provision of illness support groups” (Wilkinson & Kitzinger, 1994: p. 135).

By positioning breast cancer as a women’s health issue, breast cancer activists have succeeded in linking their claims to those already established: addressing political, social, cultural and economic barriers to women’s wellbeing, challenging discriminatory tendencies of biomedicine, and positing women as experts on their own health (Ley, 2006). This has served to legitimise the BCM in many ways, providing a solid foundation of support and working from an already well recognised platform of knowledge and activism.

In many ways, then, there has arisen a BCM that functions as both a social movement and an embodied health movement. Morello-Frosch et al., in their 2006 study of Embodied Health Movements (EHM), have discussed the key activities of the BCM as an example of such an EHM. They describe how the BCM, through the rejection of



patriarchal medicine noted above and the treatment of the body as central to the breast cancer experience, has sought to introduce the biological body to social movements and leverage embodied experiences of illness as a counter authority to science and medicine. The BCM has also highlighted scientific uncertainty to promote political and public action and challenge assumptions underlying prevention strategies, working to challenge existing medical and scientific knowledge and practice. Finally, the BCM has pioneered innovative strategies to promote lay collaboration, particularly on environmental factors, and thus have involved activists collaborating with scientists and health professionals. The BCM has also worked to affect society by producing changes in the health care and public health systems, medical science and civil society.

McCormick, Brown & Zavestoski (2003) have identified how the BCM has enabled this collaboration, by reconstructing the lines that demarcate science from non-science; blurring the boundaries between experts and laypeople; transcending the traditional conceptions of what is or is not a social movement, by moving fluidly between lay and expert identities, and across various organisational forms; and using 'boundary objects' (e.g. – pink ribbon) that overlap different social worlds and are malleable enough to be used by different parties. This fluidity also enables professionals to play varying roles over time, so that a 'expert' may also form part of the movement itself.

Klawiter (2008a) has described the BCM as an example of what she calls 'a social movement without the sovereign', which is both a poststructuralist and feminist position. In these kinds of social movements,

“bodies figure not only as sites of organic suffering and targets for the inscription of power but also as sources of subjectivity, anchors of identity, and flexible, expressive symbols and signifiers of competing discourses and practices of health, normality, risk, deviance, disability and disease” (Klawiter, 2008a, pp. xxix-xxx).

Klawiter (2008a) describes three 'cultures of action' to the BCM: early detection and screening activism (characterised by hope, gratitude, individual heroism and faith in med and science); patient empowerment and feminist treatment activism

(characterised by anger, but also compassion); and, cancer prevention and environmental activism (characterised by anger).

As Klawiter points to here, a strong element of the BCM has been the Environmental Breast Cancer Movement (EBCM), which arose in the early 1990s in response to the lack of understanding about aetiology and a potential link to environmental contaminants (Morello-Frosch et al., 2006). The EBCM works towards four goals: to broaden public awareness of potential environmental causes of breast cancer; to increase research into environmental causes of breast cancer; to create policy that could prevent environmental causes of breast cancer; and, to increase activist participation in research (McCormick, Brown & Zavestoski, 2003).

Ley (2006) has explained how the EBCM has used the platform of the women's health movement to create a population-based orientation, which has enabled activists to transform breast cancer from a personal issue into a collective one; legitimated activists' analysis of the environmental breast cancer problem's gendered dimensions; and build collective support from feminist activists working in existing fields.

Because the EBCM traces breast cancer to environmental causes, the success of breast cancer treatment, research, and even the movement itself is redefined in these terms. Prevention is seen to have failed at the point of *diagnosis*, rather than at the point of mortality (McCormick, Brown & Zavestoski, 2003). Research is considered of particular importance, particularly in the setting of the research agenda (Abma, 2006) and the involvement of breast cancer patients and activists has impacted upon research design, accrual and response rates (Hubbard, Kidd & Donaghy, 2008).

It is not only the EBCM that has challenged biomedical orthodoxy. The entire BCM

“subverts that status quo by taking a broader view of responsibility. In doing so, the movement is able to create a new value system for science. They do this by pushing scientists to examine why they ask certain questions and not others, why they use certain methodologies, and, more important, by pushing them to examine how their research affects women with breast cancer” (McCormick, Brown & Zavestoski, 2003: p. 571).

Breast cancer activism, then, depends strongly on the nature of the disease as both personal *and* political, and women as patients are encouraged to also become political activists. Patients are seen to have an active role to play, in

“teaching the biomedical community ‘new tricks’ in the form of discussion, confrontation, and testimony concerning research on breast cancer as well as extant methods of detection and treatment for the disease” (Anglin, 1997, p. 1404).

Longo, Patrick and Kruse (2001) have argued that much of this involves patients acting as not just activists, but as consumers. They describe this as occurring within an information-rich environment, including information on the disease, on self-care, on health care services and treatments, on healthcare providers and on insurance coverage, as well as in the context of personal circumstances and experience. Despite the victories achieved through this kind of activism, it is cause for concern that this dual patient responsibility, to both their own recovery and a socio-political movement, may further burden women afflicted with breast cancer.

The prominence of activists has also raised warnings, particularly the potential for cooptation by pharmaceutical companies and that the movement is less than representative, dominated as it is by white, middle class women (Anglin, 1997). There are also concerns that the focus on breast cancer activism may obscure the legitimate claims of other causes, through the kind of single-issue problem raised earlier, although what Ley (2006) calls ‘disease kinship’, that those affected by conditions with similar aspects may develop common support and interest groups, thus demonstrating what Rabinow has termed ‘biosociality’ (Rabinow, 1999), may also result.

The very activities of activists have also been criticised. Breast cancer advocates are not a homogenous group (Brenner, 2000); they have different aims, hopes and strategies. Klawiter (2008a) notes the concern of some activists that “the hegemonic discourse of survival and the omnipresence of pretty pink ribbons distorted the ugly realities of the disease” (p. 169). Similarly, while some breast cancer advocates (particularly those involved in patient support) have argued for the importance of

‘stepping out of the victim role’, by acknowledging the ways in which women *have* been victims (Wilkinson & Kitzinger, 1994).

The BCM is composed of numerous and diverse interest groups and individuals. The level of activism that has occurred around this issue has transformed it into a political issue as well as a personal one; something that has not occurred with endometriosis or WCPP.

In New Zealand, the First National Conference for those affected by breast cancer was held in 2007. The recommendations made by this conference indicate the political sway participants consider they may have in setting the agenda. The most policy-relevant of these recommendations centre on access to care, environmental health and the need to reduce inequalities.

The conference identified key objectives in improving procedures for BreastScreen Aotearoa, such as better communication with women regarding mammograms and eligibility; that the programme be increased to include women from 40-45 and 69-79 years (as in Australia); that mammographers are supported to continue to ‘renew’ existing skills to meet training requirements; and, that it should be the patient’s choice to receive results from mammograms or not. These recommendations immediately present some of the key tensions between the goals of advocacy groups and policymakers. For example, while patient or consumer groups may advocate for the extension of the programme to both younger and older women, the benefit may not be considered sufficient to justify the cost; the tough reality is that not everything can receive funding (Baker, Wall & Bloomfield, 2005).

In relation to the final objective, it is interesting to note that the National Screening Unit (NSU) currently states that only ‘some’ women will be contacted in the case of an inconclusive result (NSU (N.Z.), 2009b) in accordance with set standards (NSU (N.Z.), 2004), which means that women are being denied information and there is a slight risk of breast cancer remaining undetected due to this inaction.

This conference also called for improved access to drug treatment, stating that there should be full consultation with relevant, appropriate and representative consumer

groups; early and timely consultation with consumers; adequate time for consumers and consumer representatives to respond to proposals so that consumers may meet, reflect and consult; that consultation with consumers should be two-way, open and accountable; and, that consumer advice/input should be appropriately resourced (Breast Cancer Network (N.Z), 2007a).

Again, these recommendations are likely to conflict with policymakers' ideas. While public consultation is considered an important part of the democratic process, as has already been discussed, this is becoming less common in New Zealand, where technocratic expertise is increasingly valued (Blank, 2001). As patients are unlikely, or considered unlikely, to have such expertise, even if this consultation were to occur, it is questionable what effect it might have. Perhaps of even greater concern is that regardless of the government's general attitude to public consultation, it seems likely that the level being called for here is likely to markedly slow progress.

The conference also calls for improvements in other areas, particularly the provision of breast care nurses to private patients and improved funding for District Health Nurses (Breast Cancer Network (N.Z), 2007a). These are issues of health policy, and that this conference felt they were in a position to make such recommendations indicates the strength of breast cancer activism in New Zealand and the public and political awareness they have been able to raise.

As has occurred in the wider BCM, the conference has gone beyond the biomedical approach and has also considered environmental health. In doing so, they have called for measures that fit better into the public health or health promotion paradigm. The recommendations made include that education of New Zealanders regarding environmental influences on the development of breast cancer be addressed and implemented as a key priority; girls should be made aware of the issues at puberty: */ Here* should be an information/education pack for girls at intermediate school on breast awareness, and awareness */* raised through social networking sites like Bebo; a submission on the issue should be made to the Ministry of Education; expectant mothers should be educated about environmental influences on breast cancer development and Plunket nurses throughout the country should be educated; and, men should be included in education initiatives (Breast Cancer Network (N.Z), 2007a).

Interestingly, the stated reason for this last point is that men need to be well informed to advise their daughters. This raises a number of concerns. Firstly, it reinforces a view of women as incapable of making decisions without their patriarch, thus perpetuating the idea of women as powerless and foolish. It also implies that the only time a man can be involved in supporting a breast cancer patient is in the role of father; he is disempowered in relation to his wife, mother, female relative, friend, or colleague. The role of a man as medical practitioner or health professional is also overlooked. This statement, in keeping with the tone and fervour of feminist breast cancer activism, also implicitly restricts men from being advocates or activists in the BCM. Perhaps most concerning of all, it ignores that about 1% of breast cancer patients are male (NZBCF, 2009) (just as it is commonly overlooked that men also suffer from chronic pelvic pain, and, on rare occasions, endometriosis).

These recommendations would require a wide-scale public education programme, as they call for the raising of public awareness, rather than patient education. This effectiveness of this kind of public communication strategy has been questioned (McGuire, 1984). Apart from issues already discussed with regard to other recommendations regarding practicality, feasibility and cost, these recommendations also raise issues to do with the coercive nature of health promotion. Certainly suggesting that girls going through puberty should be made aware of breast health raises questions of whether submitting young girls to such sense of risk is socially responsible and ethical, particularly when their chances of the disease at such a young age are so rare and there is little that can actually be done even in the way of prevention or screening at this point.

## **Conclusion**

The comparative analysis of these two conditions helps to highlight the different status of these two health issues. While breast cancer is the subject of a significant amount of policy and public attention, WCPP and even endometriosis have not yet succeeded in garnering this kind of support. The following chapter will attempt to illustrate how endometriosis and WCPP can achieve a place on the policy and public agenda, given the lessons that can be learned from breast cancer.

## CHAPTER FIVE

### GETTING ON THE AGENDA

#### Introduction

This chapter considers what needs to happen and what needs to be done in order for WCPP to gain a place on the public and policy agenda. The agenda-setting perspective outlined in Chapter 1 will form the framework for this discussion.

The central issue for WCPP is that the issue is typically seen as medical, not political, in nature. Because of this, it may not readily feature on the policy agenda of its own accord (Blank, 2001).

#### Agenda Setting

Chapter 1 identified the critical components in agenda setting to be issue identification, filtration and definition, and may involve the setting of alternatives. The ability to get an item onto an agenda was also shown to be linked to the existence of a 'policy window', which opens in the political stream at a point of convergence between problem, policy and political streams (Kingdon, 1995 [1984]). If agenda setting is, as Soroka (2002) has suggested, the study of issue salience, then the question for those wanting a place for WCPP on the policy agenda is how to demonstrate the salience of this issue.

Carmines and Stimson (1993) suggest that issues themselves have different potentials, for organic extension, which are generally new issues with novel content, but which are interpreted as continuing existing conflicts, and so their capacity for eliciting change is limited; unsuccessful adaptations, issues that may capture attention, but not for long, usually because they are too complex or technical; or issue evolution, those that are capable of altering the political environment.

Hogwood and Gunn (1984) suggest the characteristics of an issue that may determine this potential. They have noted that for an issue to reach the agenda, the issue must take the form of a crisis that can no longer be ignored, demonstrate particularity (i.e. –

an example of a wider issue has become apparent), have a strong emotive aspect or wide impact, raise questions about power and legitimacy in society, and be fashionable. While Hogwood and Gunn note that even one of these criteria may be enough to propel an issue onto the agenda, the existence of more than one is certainly favourable. As Baggott (2000) has stated, policy development relies on coincidence between the processes that identify problems, the processes that promote ideas on how to tackle problems and the processes of decision making and public debate. Similarly, Hansen and King (2001), in their examination of immigration and sterilisation policy in Britain and the United States, have suggested that ideas are more likely to be translated into policy when there is synergy between ideas and interests, actors possess the requisite enthusiasm and institutional position and timing contributes to a broad constellation of preferences that reinforce those ideas.

Hogwood and Gunn's identification of a 'crisis' is common to studies of agenda setting. Kingdon has suggested that problems are often recognised due to 'focusing events', although he claims that these are normally accompanied by a pre-existing awareness of the problem, early warning, or in conjunction with other events that highlight the problem (Kingdon, 1995 [1984]). Birkland (1998) has suggested that these focusing events change the dominant issues on the agenda and may lead to interest group mobilisation. The types of crises normally described as motivating this kind of policy change are things like natural disasters, industrial accidents, economic calamities or wars (Birkland, 1998). However, examples can also be seen in health policy, such as the 1988 Cartwright Inquiry (or the article that spawned it, *An Unfortunate Experiment*), which criticised as unethical research done on cervical cancer patients in Auckland's National Women's Hospital (Women's Health Action Trust, 2009).

To date, WCPP appears to be lacking this sort of triggering mechanism. Another problem is that the condition is not a topic that is currently, or is ever likely to be, 'fashionable' in the sense that Hogwood and Gunn suggest is helpful, as the topic is normally considered to be 'private' one. There may have been some potential for such an issue to come into vogue at the height of the women's movement, when feeling about gender discrimination ran high, but this time seems to have passed. However, the issue does have both strong emotive aspect (suffering) and considerable impact (in



terms of prevalence). As Chapters 2 and 3 have discussed, WCPP also raises questions about power and legitimacy in society, particularly of biomedicine. Most importantly, the issue does now demonstrate particularity, in both the form of infertility (which may itself be seen as a trendy, or 'fashionable', issue) and more obviously, endometriosis.

While endometriosis may be beginning to feature on the public agenda, it has already been noted that this is insufficient for it to find a place on the policy agenda. Blank (2001) in his study of agenda setting in the New Zealand health system has described the policy importance of a problem as depending on both public response and relationship to organised economic and political interests. Howlett and Ramesh (2003) have emphasised that

"Problems come into discourse and therefore into existence as reinforcements of ideologies, not simply because they are there or because they are important for well being. They signify who are virtuous and useful and who are dangerous and inadequate, which actions will be rewarded and which penalised. They constitute people as subjects with particular kinds of aspirations, self-concepts and fears, and they create beliefs about the relative importance of events and objects" (Howlett & Ramesh, 2003: p. 121).

Problem definition is a crucial part of agenda setting because the way a problem is defined influences its chances of reaching both public and policy agendas. Rochefort and Cobb (1994) have noted the key elements of problem definition rhetoric: causality, severity, incidence, novelty, proximity (i.e. – relevance), crisis, problem populations (i.e. – applicability), and solutions. The difficulties in applying these devices to WCPP have been outlined in Chapters 2 and 3, but it is these rhetorical elements that advocates for WCPP need to utilise in order to achieve a place on both public, and more particularly, policy agendas, as this is the language of politics. In the same way, problem definition is a crucial part of creating policy narratives, which "underwrite and stabilise the assumptions for policymaking" (Roe, 1994: p. 34). An important part of this will be to formulate an adequate explanation of the nature of the problem, as this is central to its acceptability by both the public and policymakers (Edelman, 1988).

This is not as straightforward as it seems. WCPP is commonly claimed as a biomedical issue, but when it cannot be successfully treated in this framework, or organic pathology cannot be found, it tends to be shunted into biopsychosocial studies. It is commonly noted that the dilemma for a condition such as WCPP is that it relies upon biomedicine at the same time as it is ill-served by it (Whelan, 2003; Nichter, 1998; Bury, 1982). It may be that a decision needs to be made about which framework the issue can be best understood within, rather than the compromise situation that seems to currently exist. This means acknowledging the potential benefits and shortcomings of each, as well as identifying which is most likely to be politically viable. It will also affect the types of strategies that are adopted. For instance, if the decision is made to attempt to frame the issue in a biomedical sense, then the focus may become on seeking funding for research, as better understanding of aetiology and pathogenesis are required.

It is also important to note that policymaking frequently occurs in ways that do not operate in the linear fashion that is often assumed for the purpose of policy analysis. It is important to also consider the 'messy reality' (Martin & Salmond, 2001) of policymaking that is often "sloppy and complicated" (Bosso, 1994: p. 201) rather than neat and organised. Policymaking often consists more of discovering a *solution*, before a problem has been identified, than the recognition of a problem and the rational consideration of alternative solutions to that problem. This may be particularly likely in terms of the 'technological fix', which often has a degree of excitement attached to it. Advocates for WCPP will be well served by considering also whether there are any 'solutions' that could be presented that might hasten the process along. The LNG-IUS (Mirena) may be one option here; lobbying PHARMAC for better funding of this may be of use in gynaecological-related WCPP.

It may also be that what is needed is wide-scale reconfiguration of the health system with regard to chronic care (Dixon et al., 2004). Greco (2003) has suggested that patients with chronic pelvic pain may be best served by the kind of individualised, multidisciplinary care that can be provided through the likes of a pain centre or chronic care clinic. This would involve making care available from the necessary specialists (whether gynaecological, gastroenterological, urological or

musculoskeletal), as well as pain management therapies, cognitive and behavioural therapies and emotional and psychological support. Stones (2002) has suggested that early intervention, *before* the condition has become chronic, would be most beneficial. This could perhaps be achieved by referring women undergoing diagnostic laparoscopy to such a clinic at the time of surgery. This might also help to reduce costs, which are most heavily incurred in the first year after onset (Kronborg, Handberg & Axelsen, 2009). Kirby, Dunwoody and Millar (2009) have suggested that this could even be achieved within primary care, but that this would rely upon general practitioners employing a more holistic approach, rather than a purely biomedical one.

Platt (2005) has examined the rise of the issue of child poverty to policy agendas and emphasised the importance of mobilising traditional and conservative actors, as well more radical and single-issue campaigning. In the same way, the BCM has successfully modelled itself on other social movements, and advocates from WCPP should be able to see a clear path from this. Benefits may be gained from incorporating aspects of the women's movement and environmental health movement. It may well also require mobilising a more traditional power base (i.e. – the medical profession).

As has been explained in Chapter 2, healthy public policy relies upon the involvement of many different governmental and non-governmental agencies. Individuals, organisations and government departments each have “certain inherent limits on their ability to perceive problems” (Brewer & deLeon, 1983: p. 39). It is therefore important that the issue is defined so as to cope under the control of a governmental authority fitted to cope with it, as

“those issue that are commonly perceived by elite members of the political community as meriting public attention, and that involve matters within the legitimate jurisdiction of existing governmental authority, are defined as part of the public agenda” (Gerston, 1997).

The most likely authority to be identified is the MOH.

It is useful to consider the kinds of questions a governmental authority of this kind may be considering once the issue has come to their attention. It is not enough simply

to raise awareness; the issue must also be ready to function as a policy agenda item. Hogwood and Gunn (1984) have outlined the questions that may be raised:

<b>Issue's context</b>	<b>Issue's internal characteristics</b>	<b>Issue's repercussions</b>	<b>Costs of action and analysis</b>
Is there time for analysis?	Is there scope for choice?	What scale of consequences is involved?	How large are the costs?
To what extent does the issue have political overtures?	How much consensus is there about issue and solution?	How many people will be affected?	Costs incremental or quantum jump?
Have fixed positions been adopted?	How complex is the issue?	How significant are the affected groups?	For how long a period will resources be committed?
How central to the concerns of the organisation is the issue?	How much uncertainty is involved in the issue?	How significantly is the group affected?	What will the cost of analysis be?
	How value-laden is the issue?	Is the issue likely to ramify and affect other issues?	Will the analysis have pay-off?
		Will acting upon the issue restrict the agency's future flexibility of action?	

A consideration of these kinds of queries prior to extensive effort in getting WCPP on the policy agenda may focus energy in the right place and better serve this important issue.

It is also important to remember that it is not always the issue itself that is responsible for its place (or non-existence) on public or policy agendas. Cobb and Elder (1971) suggest that it is often the group advancing the issue that struggles to gain legitimacy, rather than the issue itself. In terms of WCPP then, the lack of a unified effort to advance the issue onto an agenda may be identified as a crucial hindrance. By contrast, endometriosis, a specific instance of WCPP, has begun coordinated efforts for recognition of this issue. To this end, the Endometriosis New Zealand Trust Board is comprised of not only long-time advocates Deborah Bush (the Chief Executive) and Margaret McKenzie, but also gynaecologists such as John Doig and Simon Jones,

which serves to provide expertise and credibility in the biomedical arena. (This is also an instance of how medical professionals may also function as members of interest groups or social movements, as has been alluded to previously). This kind of legitimacy is critical in advancing this issue.

### *Media*

The media may also be important in garnering support for WCPP as an agenda item, particularly in elevating it to the public agenda. Obviously the key activity of the media is awareness-raising, although the actions of the media may also influence issue definition.

The media are one means by which an issue may seek to mobilise itself. The media is able provide information, generate public attention, stimulate debate and encourage policy responses (Bertin & Beck, 1996) through both shaping public opinion and policymakers' perceptions of public opinion (Bakir, 2006; Jeon & Haider-Markel, 2001). Karpf (1988) has explained how the media

“plays a significant role in shaping public debate and the climate of opinion, both in what it chooses to address and what it doesn't, through its ‘symbolic crusades’ and moral panics, its sudden creation of social problems, its ongoing obsessions and its routines omissions.

This is the media's agenda-setting role” (p. 230).

Downs (1972) uses environmental policy in America to examine what he describes as the ‘issue-attention cycle’ in public policy. The control of this issue-attention cycle is seen by Downs as resting with the media, who, for profit motive, are compelled to appeal to the largest audience. Downs suggests that the perception of policy issues reflects this issue-attention cycle, more than it does the ‘reality’ of changing social or political conditions. He identifies five stages in this cycle: the pre-problem stage (the problem exists, but has not been recognised), alarmed discovery and euphoric enthusiasm, realising the cost of significant progress (often accompanied by attempts at a technological fix), gradual decline of public interest, and the post-problem stage, which Downs describes as “prolonged limbo – a twilight realm of lesser attention or spasmodic recurrences of interest” (Downs, 1972, p. 41).

The institutions, policies or programmes that may have been established during this time may often remain.

Not all problems are expected to go through this cycle. Downs suggests that issues most likely to be those where the majority of people are not suffering so much as a minority, and that that suffering caused by the problem are generated by social arrangements, in which case there will be a lack of sustained interest. If the problem is not seen as having any intrinsically exciting qualities, it is also likely to fade. Downs considers that those problems that have gone through the cycle receive higher levels of attention, public effort and general concern than those in the pre-discovery stage, but the passage of an issue through this cycle also means that it will fade from public attention.

Using the media is fraught with complications. One problem is that medico-scientific findings are not normally articulated in such a way as to make them conducive to reproduction in media outlets. In 'decoding' science for the purposes of creating news, the context of research may be lost (Bertin & Beck, 1996), and this is one reason the media may be accused of sensationalism or alarmism (Karpf, 1988). This is reinforced by findings of stronger responses to news items designed to generate fear (Young, 2003).

The public may also become 'saturated' by certain types of information or story, resulting in apathy rather than interest. Morton and Duck (2001) have investigated the role of the media in portraying the risk of skin cancer, and have noted that people are more likely to think of this risk in terms of others, rather than themselves, in the same way as Hafferty (2006) warned, as noted in Chapter 2, that the people may become desensitised to health issues, which could be seen as partly attributable to the media.

In her study of medical programming, Karpf (1988) has examined how the portrayal of medical issues by the media encourages the consumer approach to healthcare. This is not necessarily a negative thing; Karpf notes that such programming may serve to inform and empower patients, especially against the dangers of iatrogenesis. She also suggests that the media may reinforce the tenets of health promotion by emphasising to the audience "how to avoid illness, not what to do when they had it...how to stay

away from the doctor, not how to get more from him or her” (Karpf, 1988: p. 18). The media’s role may thus place responsibility for health upon the individual (or consumer). The problems with this have already been described in Chapter 2, and in terms of agenda, it may remove the prerogative of government to intervene.

Of particular difficulty for WCPP is the tendency of media to “seize on the exceptional rather than the typical, on glamorous, life-threatening diseases rather than the commonest ones” (Karpf, 1988: p. 27). Similarly, Baumgartner and Jones (1991) have noted that “public discourse when traced over long periods of time tends to show a fascination with one aspect of the issue to the exclusion of the other, at any given time”(p. 1046). WCPP may also be plagued by the problem described as ‘accessibility bias’; that is, that information that is more easily recalled tends to dominate opinions and judgement (Iyengar, 1993). This accessibility bias applies at the level of both the media itself and the audience. Because cultural values shape news (Iyengar, 1993), WCPP may also suffer from the taboos around issues of women’s reproductive health. This also means that the media have a special responsibility in reporting on such topics.

Of course, the importance of the media should not be overestimated; the media are not omnipotent in setting the agenda (Peterson, 1990), nor can the importance of an issue be determined from the level of media coverage given to it (Soroka, 2002). Edelman (1988) has explained how public attention may be both present and absent, as “(t)hose who assume they cannot influence a condition do not clamour for governmental action to change it” (p. 32).

### *Academia*

Academia, as an important source of the development of ideas in policy studies (Hill, 1993), is a potential supply of pressure in raising items to both public and policy agendas. For it to be used to this end, chronic conditions must come to be seen as a legitimate area of enquiry for not just medicine, but also the social sciences and humanities. One of the difficulties in doing so is that, at the same time as such conditions have been medicalised, they have been under-theorised (Clarke & Olesen, 1999). Anderson (2003) has asserted that the turn of the century marked a turning

point in social sciences, with alignment to public policy rather than scientific progress, indicating that work in this field may now better apply to this kind of topic. Valuing qualitative research will also be of importance here (Murray & Chamberlain, 2000; Traweek, 1999).

There are efforts that can be made to improve the usefulness of academic research. Davis and Howden-Chapman (1996), in their study of the translation of research findings into health policy, suggest that research is “more influential if topical, timely, well funded and carried out by a collaborative team that includes academics” (Davis & Howden-Chapman, 1996: p. 865), and emphasising the responsibility of researchers to consider the policy implications of their research.

### **Conclusion**

It seems that there are a number of options available to those advocating for WCPP. These must be carefully considered, as decisions made now will form WCPP’s policy image (Baumgartner & Jones, 1991). Perhaps the wisest advice is that given by Brewer and deLeon to policy analysts. These authors suggest that

“the analyst should prepare a menu of policy alternatives that cover the range of appropriate, possible, and feasible solutions to the problem. The range might well include inaction or radical action. It should be varied enough to permit the decision maker to choose between different capabilities, technologies, resources, and policy levers” (Brewer & de Leon, 1983: p. 65).

It is absolutely critical for the agenda advancement of WCPP that greater consideration be given to the issues explored here. This condition brings together a diverse range of issues that have much to teach public and policymakers alike about our understanding and valuing of health. It is time that WCPP is discussed seriously as a potential agenda item, one that can be a trailblazer for women’s health.



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